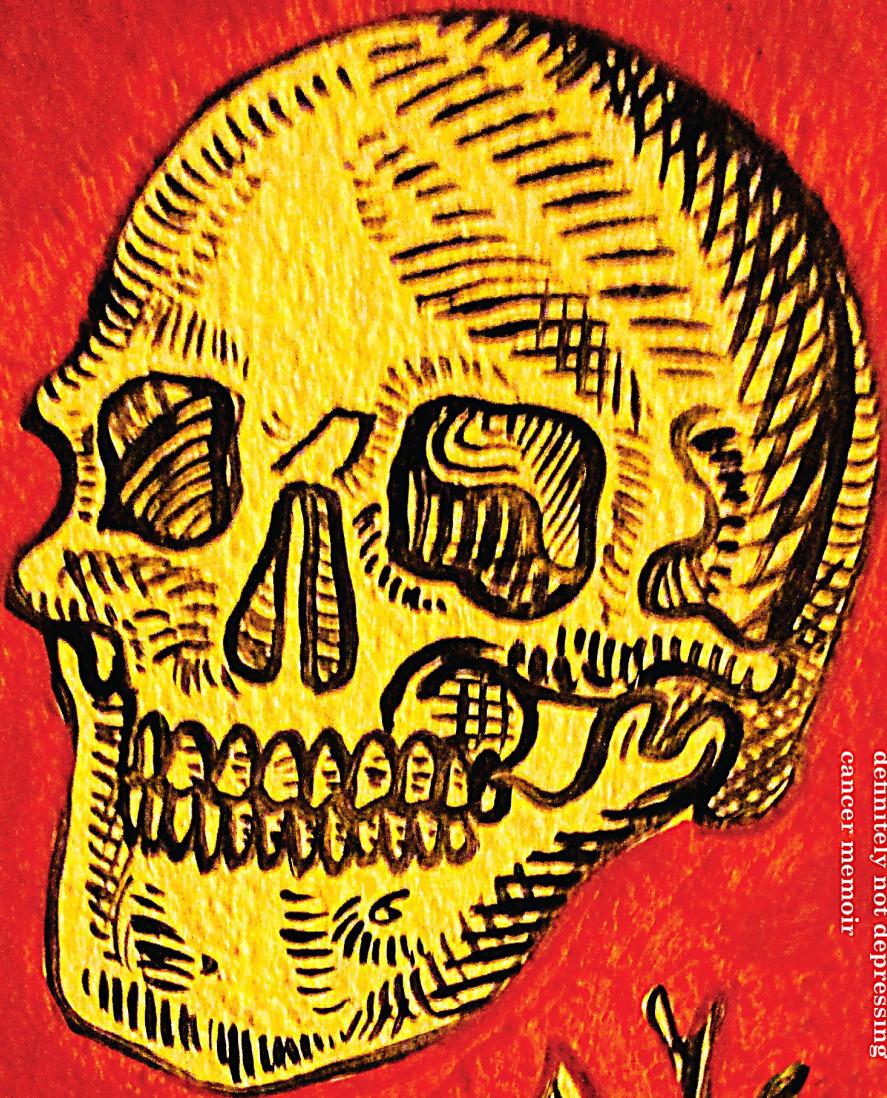


Crap, I've got Cancer

Suvanna Lisa Cullen

The sad, somewhat funny,
definitely not depressing
cancer memoir.



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'If you have already been strapped into that very particular roller coaster that is cancer – and if you have not – my wish is that this book will both entertain you and help you to understand more deeply and appreciate more fully the miracle that is your life.'

This edition published to mark the first anniversary of Suvanna's death.

[The Buddhist Centre Online](#)

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"We Still Can't Believe It"



Funny

how

in the light of death

everything

shines!

from *Petals* by Rick Fields

Thanks

Many thanks to Suvanna's sisters, Laura, Kathy and Paulette, for their generous help with getting this book printed, to Dhammarati for giving so much time and care to designing the original book, to Hridayashri for her help with finding and preparing the photographs, and to Padmatara and Candradasa for all their support.

Suvanna loved poetry and often quoted on her blog the poems that spoke to her on that day, so it seemed very important to include those poems in this book. I've written to all the copyright holders, as far as I've been able to find out who they are, explaining the nature of this book and asking their permission to quote the poems. I haven't heard back from all of them yet, but want to express my thanks and appreciation in advance of this publication.

Editorial note

In December 2012, Suvarnaprabha sent me an email: “I don’t know if you have heard but I am in fact dying of cancer. I have been writing updates on a blog for the last year, and would very much like the blog to be edited into a book. Many people told me they thought it would be relevant to people who don’t know me, as their sisters or moms or whatever are reading it. (Or maybe they were just humoring me!)” And that’s how this book began. Suvarnaprabha was the one who found herself strapped into the roller-coaster, as she put it, from the moment she was diagnosed with a rare form of cancer (“I like to think of myself as the albino tiger of the oncology department”) but with typical generosity she took all of us with her for the ride, finding so many ways of saying the (horribly) unspeakable and expressing the (deeply) inexpressible.

She wanted to finish this book herself, and had very specific ideas about how she wanted it to be, but in the end she had to leave it to her friends to finish it for her. The book in your hands is her gift to you today. An idea we had quite early on was to include some of her earlier writings, both prose and poetry, interspersed between the months of her cancer blog entries. She had a gift for saying things, and a gift for meaning them, and feeling them; she clearly had a lot more in her to write, and we wanted this book to include as many as possible of her words.

The blog entries are presented here pretty much as they were written. Some of the medical details have been cropped a bit, and a few of the wilder digressions seemed not to want to stay, though many of the wildest kept sneaking back in. There's a whole cast of characters – we get to know Suvanna's friends and family through their frequent appearances, and many doctors and nurses, both real and fictional, also feature (here they're given initials rather than names, according to a cunning coding system devised by their considerate patient...)

There's a fair smattering of Buddhist names and Sanskrit terms to contend with – if you're not familiar with them, just breeze past them as Suvarnaprabha herself would advise. When I asked her about her name in an email, she said, "I'm Suvarnaprabha to Buddhists and Suvanna when not in Buddhist company, though some Buddhists call me Suvanna, but they're not supposed to!" By the way, Suvarnaprabha is a Sanskrit name (given to her when she was ordained into the Triratna Buddhist Order in 2001) meaning "golden radiance".

Suvarnaprabha never shied away from writing about her approaching encounter with the grim reaper, to use one of the politer and more conventional ways she referred to that mysterious process, but whatever was going on and however she felt about it, through all the medical appointments and appearances of Nurse Jackie, the journeys and movie recommendations, her delight in good friends, the moments of sadness, stoicism, drama and farce, the underlying

theme of this story, as I'm sure you'll agree, is not really 'cancer', or 'death' at all, but love.

Vidyadevi, November 2013

Foreword (John Wilson / Paramananda)

Late Fragment

by Raymond Carver

And did you get what
you wanted from this life, even so?

I did.

And what did you want?

To call myself beloved, to feel myself
beloved on the earth.

*

A few days after learning about Suvarnaprabha's terminal diagnosis with cancer, I was talking to a friend and found myself saying that it was such a shame as she had so much to offer as a teacher. My friend said that maybe her death would be her teaching. I don't think I found those words particularly helpful at the time, but over the next two years they came back to mind often and were to prove prophetic. On reflection, how could it have been otherwise? Suvarnaprabha embodied her Dharma practice in an unusually deep way. I do not mean to imply that she was a 'perfect' Buddhist, but rather that she was more or less without any front. She was in equal measure

vulnerable, honest, profound and neurotic. When she died I found a little refrain going through my mind which went ‘She was big boned, big mouthed and big hearted’. She was one of those rare people who made an impression that stayed with you and kept inspiring you. Oscar Wilde once said ‘Most people are other people’. She was one of the rare exceptions.

A few months before she knew she was ill we were leading a month-long retreat together in a field in Devon in the west of England. It was two years later, at the time of the same retreat, which we had planned to do together again, that she died. About half of the people on that second retreat had also been on the earlier one I taught with Suvarnaprabha, and it was a comfort for me to be with some people who remembered her. People spoke of their memories, and what stuck in their minds was all the laughter between her and me. It was a delight to work with Suvarnaprabha, who had become a very dear friend over the eight years in the nineties when I lived in her home town of San Francisco.

For most of that time we both lived above the [Buddhist Center](#), she on the top floor in a small women’s community, and I on the first floor in a small men’s community. We shared a deck and there was a great deal of contact between us all. We became close friends partly perhaps because we shared a love of poetry as well as Buddhism but more because we just naturally felt at ease with one another.

Suvarnaprabha was a complex woman. She was tough and down to earth and on the other hand – there was always the other hand with

us both – she was incredibly smart and sensitive, vulnerable and beautiful. I never tired of her company as she was brimming with life and kindness.

We had many adventures together. I am sure she would not mind me saying that LSD, so associated with San Francisco, played a part in some of them. I also remember swimming together at night in a phosphorescent sea in a moonlit Mexican bay with dolphins sporting close by. These and many other memories come back to me now.

I am very grateful to have been able to visit her earlier this year. She was still well enough to go out, and in many ways she was much her old self. What had changed was that there was a new gravity to her. A stronger sense of weight and care, of being more fully in the world, more intimate with those around her. It was very striking, the love that surrounded her and in a sense also sprang from her. She gave courage through her vulnerability, her sense of care towards herself and others. She played a pivotal part over two decades in building a vibrant and exceptionally close Sangha, or community, around the San Francisco Buddhist Center. She was loved because she allowed people to know her, she wore her heart on her sleeve and it was a big and open heart. Her blog, now published here, gives a sense of what I am trying to say. Her personality shines through all the medical appointments and treatments.

The 'Late Fragment' that heads this foreword is from a writer she introduced me to, and his words seem to me to express the teaching that she gave all her many friends and now offers to you all.

Introduction: Strapping into the Roller Coaster

A vegetarian and a Buddhist meditator for over 20 years, I have enjoyed good health (though not enjoyed it nearly enough!) until the last couple of years. When I was around 47, I became increasingly fatigued, started having my period every three weeks, and found myself dealing not very often, but way too often, with devastating depression. Then after an increase of symptoms (really just things that tend to happen to no small number of women my age) I was diagnosed with Stage 4b vaginal adenocarcinoma. A formal introduction to the Grim Reaper.

Buddhist practice is super helpful at times like these, and at many others. However I want to let you know that I am not going to be explaining Buddhism or Buddhist practice in this book. Thankfully there are thousands of other books that do that. (Please consider buying one of those books, especially if you are in the US and heard about Buddhism from your church!)

So what follows is a play-by-play of my life since my diagnosis, less than two years ago: part humor, part philosophy, and part medical update. It is derived from a blog I created for friends and family who have encouraged me to share it with others. On it, I wrote, drew, photographed, reported, and reflected upon what was happening, inside and outside. It chronicles the new lens I am using to see,

conjured by suffering and reflection upon death. All of which sounds rather heavy, and it is from a certain point of view. From another, it is just something that happens to everyone and something most of us are actively ignoring for most of our lives. It is something I am currently trying to embrace, though sometimes my arms fly up into the air, as they would on any roller coaster ride.

Anyhoo. If you have already been strapped into that very particular roller coaster that is cancer – and if you have not – my wish is that this book will both entertain you and help you to understand more deeply and appreciate more fully the miracle that is your life.

Suvanna Lisa Cullen

Mexico D.F.

November 2012

Timeline of Trouble

May 6, 2011

Normal annual gyn. exam. Perimenopause ongoingly problematic, but not unusual (frequent periods, fatigue, depression). My nurse practitioner suggested fluoxetine for mood stabilization and helping with other symptoms of perimenopause.

October 3

Period starts, and doesn't stop. Experiencing a lot of fatigue.

November 4

Same day appointment at my health plan with a new (available) doctor. Many subsequent appointments – which included a vaginal biopsy, a uterine biopsy, an ultrasound, and a CT scan. The doctor didn't tell me that I have cancer, or at least he didn't use that word. So I did not get it.

December 6

I thought they did not have a real diagnosis and started seeing an acupuncturist, who asked for medical records. Poking around online in my records at around midnight, I looked under "Ongoing conditions" and found out I have cancer! Diagnosis dated November 21. I alternated between shock and denial. Was it a clerical error? Was the doctor insane? If it were true wouldn't he have told me? I didn't really believe it until I called the doctor the next day. Looking back on it, it was all rather obvious, but since I figured I'd be the last person on

earth to get cancer, I really needed to hear that word in order to understand. He said he didn't want to alarm me. Yet being alarmed is... appropriate! Since I'm not naming names here, I'll just go ahead and say that his communication skills were appalling!

December 16

Meet with lovely gynaecological oncologist, poetically referred to as a "GynOnc", Dr K. "Tell me everything" was my approach. Pals Julie and Padmatara came with me to this and subsequent appointments. Dr K ordered various tests to ensure that the vaginal tumor is the primary cancer. If it is, and no other cancer is found, it is "Stage 2".

December 19

Cystoscopy ('cyst', at least in this case, means bladder) with excellent urologist Dr R. Procedure sometimes causes infection so was given antibiotics. After taking first one, broke out in super itchy hives. Note to self: allergic to sulfa drugs.

Upcoming appointments: pelvic x-ray on my way home from Lake County, at Geary.

Solitary retreat Dec 22-27 – yay!

December 20

PET scan (Positron Emission Tomography) in Santa Clara. They shoot you up with radioactive sugar (a quote from the nurse who explained it to me), leave you lying down in a dark room for about an hour, then

spend about 20 minutes in a CT-scan-like machine which is a lot more sensitive. It finds areas of sugar = intense metabolic activity.

December 21

Went with Padmatara to a two-hour **chemotherapy** class. Very helpful. Got this note from Dr R, the urologist, "The cytology report does show tumor cells in the urine as expected. You should talk to Dr K about this and about the PET-CT when those results are available."

December 22

Notes from conversation with Dr N (backup while Dr K is on vacation): The tumor cells in the urine mean just that the cells are around, not that the cancer has traveled to the bladder. PET scan doesn't show another origin; this test is not very specific – did light up pelvic bone near tumor – could just be mass itself. Should get x-rays just in case. (**CAT scan** didn't show anything in bones.) Chemo usually starts 1-2 weeks after initial consult. Yes, usually gets worse/more tired cumulatively. Is the tumor growing fast? She said if there was no sign of it in May and it's 5cm now, that's pretty fast!

December 30

Julie and I spent quite a lot of time with **radiation** oncologist Dr O in South San Francisco. He let us know that the PET scan and pelvic x-ray I got showed cancer in my pelvic bone – next to the tumor. He called it sclerosis, which apparently means scarring. It was also in one lymph node. When cancer is in the bone, the staging changes to Stage 4. They have found 'no distant disease', which is the usual case

with Stage 4 cancers. The way the oncologist put it was that they can't cure cancer in the bone, so they start thinking in terms of 'control' rather than cure. It's not possible to give enough radiation to bone, so they try to take away pain and protect the bone. He did say that my general health is very good and that is a very positive factor, and that there were no fractures or holes in the bone (the worst case scenario). The penetration into the bone seems to be minor. He said the cancer was probably there when I had my last exam in May, but was not big enough to feel in a pelvic exam – and pap smears test for cervical cancer only.

We were there for a couple of hours, and I did get a chance to ask the oncologist – even though I knew he probably wouldn't have an answer – why this has happened.

He said, “bad luck”. He pointed out how extremely rare my condition is, and that nothing in my family history would ever point to this happening. In general I am doing fairly well mentally, and am not in physical pain... was greatly helped by a solitary retreat up in Lake County which was wonderful.

Will likely be 28 treatments of external radiation (each session is short, 10 or 20 minutes). Next step is to get another CT scan so they can put little dot tattoos on me to start mapping out where the radiation is going to go. At first they were saying chemo is done to enhance the effect of the radiation. That is no longer the case – chemo is primary since the chance of cancer cells being elsewhere in the body is very

high. There might be more chemo and/or internal radiation treatment after the end of the external radiation.

Effects of radiation take 2-3 weeks to kick in, and last 2-3 weeks after radiation stops. Possible short term side effects of radiation – UTI infection, diarrhoea, stinging urination, skin reactions (burning). Longer term: 15% chance of urethra blockage – can be corrected. Bladder repairs itself. Mild edema 20% chance. Radiation itself can cause new tumors. In addition, I will go through menopause within 6 months after treatment.

January 3: Room not really as divey as it appears here.

Photo, Padmatara



January 2012: The albino tiger of the oncology department

January 3: **2nd radiation oncologist**

Today Julie and I drove to Santa Clara for an appointment with Dr L, who is “one of the world pioneers in brachytherapy and intra-operative radiation therapy”. I have consistently felt that I am getting excellent care at my health plan, but from a subjective point of view this meeting was pretty depressing. I thought I was done with discoveries about my condition, but apparently not. I have one more meeting tomorrow with the chemo guy... see what happens there

In any case. Today. The point today was to find out about internal radiation which is going to be part of my treatment, in addition to external radiation and chemotherapy. I had been told that internal radiation is very simple. Turns out there are two kinds, and I'm not getting the simple kind. I'm getting the kind that is injected with needles, that you need spinal anesthesia for. Why? Because my tumor is big, it is deep. Because there is cancer not only in the pelvic bone near the tumor, but in my left hip joint (which must be why I got on my bike yesterday, went OUCH, and got off. It hurt my bones.)

I've asked the oncologists about my chances of being alive in five years. They say it depends on how the tumor shrinks, which they cannot predict. Aside from issues of survival, for me, there are major issues to do with quality of life. What level of functionality will my body

have at the end of all these toxic blasts? The doctor told me that there is a 'reasonable likelihood' that removal of the tumor will leave a hole, called a fistula, in the wall of the vagina, the bladder, or both. The nurse practitioner said that radiation impairs the ability of healthy tissue to repair itself. At that point, surgery is risky, can cause more problems than it solves. So you have to wait many months to let the healthy tissue return to closer to normal and then see what is possible.

This is what happens after every exam and meeting with an oncologist – this was my fourth besides all the tests and scans – they give me what appears to be super depressing news. I think, Are you fricking kidding me? It sounds like a total nightmare, again. Then, strangely, I get used to whatever they said. As [Shantideva](#) says, If you can solve your problem, then why worry? If you cannot solve it, then why worry? That is pretty much my philosophy. To practice this philosophy, I have to live in the present, because I can't know what the future holds.

January 4: **Medical oncologist/chemo**

Didn't get any more bad news today, or none that I'm going to tell you – ha ha! Dr S did say that my condition is so rare that there is no good data for treatment, survival rates, or... anything. As my sister Kathy said yesterday, I've always been special! I like to think of myself as the albino tiger of the oncology department.

Karunadevi and Julie came with me today. I will be getting cisplatinum, a 'radio sensitizer', meaning that its primary function is to enhance the effectiveness of the radiation. He is not concerned about herbs or

acupuncture – just advised caution in making sure there is nothing in the herbs that causes blood thinning.

Benefits of Cancer

One wouldn't want to be ridiculously optimistic, and I am not.

However, I have noticed a few things since my diagnosis:

My life now is deeply and intuitively precious to me.

At the same time, I think I will be able to let it go when I need to.

I am able to live much more wholly in the present.

I experience my life, and other people's lives, as precious.

There is a lot more love being expressed by everyone in my life (including me).

I feel very connected to people.

I told a friend in an email, who asked me if I felt supported, that I felt surrounded by love.

My family has been generous with money, without which I could not take care of myself properly.

In a way, everything has become really simple. There's just taking care of stuff, and love.

Physically, I don't feel so bad other than feeling depleted/tired, which I have been for many months (if not years).

I write these things not because I'm trying to be positive, but because this has been my experience, so far. It hasn't been very long – about a month.

January 5: **CT scan with tattoos**

I had two CT scans yesterday. A CT scanner is essentially a temperamental donut that has a camera whirling around inside of it, and you get very, very carefully placed on a table and wheeled into the center, as if you were the jam. Writing about the details of the procedure here would be rather too intimate even for me. Suffice it to say that I have three dot tattoos now. Getting a tattoo, even a tiny little dot tattoo, was way more painful than I thought it would be. They are on either hip and below my belly button, to help with navigation of radiation beams. The RN today who helped with the radiation was so incredibly thoughtful and gentle, I loved her. I'm sorry I won't be getting any more CT scans, at least not for a while. I also got a lot of info about side effects of radiation. It's finally sinking in that I'm going to lose my hair... I ordered some stuff today recommended by nurses and docs – special soap, shampoo and other things.

January 7: **Chinese medicine**

Wow, for the last, say four days, I do not feel tired! Last night I went to sleep at around 10, and woke up naturally at about 6:30. Must be because of changing my diet? Also probably getting off the depletion/caffeine merry-go-round. In any case, it is fantastic. It's also good because I need energy to clean up some things my life a bit before I start chemotherapy.

Yesterday I felt so energetic (relatively speaking) that I walked downtown (about a mile and a half). Had a strange experience on Market Street (around 9th St). At one point I looked around, and everyone seemed really friendly and happy. Sure, it was a nice, sunny day. But it was the first time I can ever recollect feeling this way, that I was surrounded by random people who were very kind. I should have blinked to see if they were still there when I opened my eyes again...

I went down there to visit Winnie (acupuncturist I started seeing before I knew my diagnosis), who lent me some books about cancer, and then had my initial consultation with [Misha Cohen](#). She is well known for working with tough cases for many years. I was there for two or three hours. It was wonderful. It feels deeply nourishing/healing to me in a way that going to my health plan does not. I have a lot of respect for Chinese medicine and in the past it has been helpful, especially on things that Western doctors can't help with.

We talked for about an hour. She was very kind, and she knows a lot about chemotherapy and radiation, even about my specific chemo drug. Then I had a treatment, which was intense. It's hard to explain. I felt a lot of intense energy moving around in my body; somehow it is also extremely meditative. She asked me about some kind of blockage in my chest that she felt in my pulse. I said yes, I have worked with blocked heart energy quite a lot. She put a needle in a point near my lower shin bone, which was rather painful, but I felt it very strongly in my left hip (where there is cancer)...

Her advice was to meditate (which I haven't been doing, mostly because of extremely low energy and painful sit bones). Re nutrition, she suggested I get [Life Over Cancer](#), which I ordered last night. She suggested fish (according to recommendations on [seafoodwatch.org](#)), whey protein, organic eggs. I think she said chicken causes some kind of congestion. On the alkaline/endless sprouts front, she said Chinese medicine recommends at least lightly cooking all foods, though sanitation might have been a big influence (it's true – seems like very few cultures [outside California!] eat raw vegetables). But I often cook the sprouts too. I don't feel like I can eat tons of raw food but I certainly like having some – carrots and turnips etc.

Meditation

I meditated twice in the Buddhist Center this morning. First time I've been in there in about a month, which probably has not happened since I moved into the building in 1994. I don't think I have meditated formally – maybe once – for a couple of weeks, which has also got to be some kind of record. I was nervous about making an appearance and being overwhelmed, but there were only around six people there, and it was in silence, so it was fantastic. Started setting up my cushions and then remembered that I can't sit on cushions, so I got a chair – enjoyed meditation but it started to hurt my joints toward the end. Second sit I was lying on the floor. I feel intuitively that the mildly painful sensations I get in my left knee, and my right hip are cancer that is not detectable yet. They feel the same way my left hip does, only subtler. It was very interesting figuring out how to relate to this

during meditation. Not only the pain but the fear about the pain, and just letting it be. I deeply love this process.

January 8: **Thanks for all your kindnesses**

My dad (in Southern California) sent me a big check, my step-mom is giving me her car and paying for parking, and her daughters are covering the insurance. These things are such a huge relief to me. And many other kindnesses have come my way. I feel so grateful that people care about me and want me to live. You might think, of course they do... but... one feels gratitude.

I was saying to Julie yesterday as we were walking in Edgewood Park, is it true that I am happier than I was before I knew I had cancer? How can that be? I suppose there is more happiness (and more sadness and terror as well). I wanted to post on the blog a picture she took of me from the back... I'm wearing a Grateful Dead sweatshirt around my waist, crouching over with a docent to look at a plant, and it says DEAD across my butt. Julie is too sensible to give it to me, but we laughed about it for a long time.

January 9: **Shaman**

My friend Alan is a shaman. On his website he describes what he does as “a practice of entering non-ordinary states of reality to engage with the spirit helpers and the natural world to develop relationships, solve problems, perform healings and enhance balance”. Alan has also been a volunteer at SF Zen Hospice for almost 20 years.

Please do not take what I write here too literally.

First we chatted in his living room. I mentioned that the lingo around cancer is 'fighting for your life'. I said I did not want to fight for my life, that the cancer is part of my body and I do not want to fight my body. That I am working on finding out what the opposite of that is. He agreed very much with this.

Then we went into his healing room (I don't know what he calls it). First thing he did was ask me to say to the shrine my intention for healing. I didn't find this so easy at first. I did realize that on some level, I do not expect to live that long. I said something like that I wanted to heal and to be able to appreciate all aspects of my life. Then I was lying on a cot, and he did a little chanting and... again, hard to describe. I had all sorts of images going through my head, but they were so quick I can't remember them. My lower abdomen started to hurt, and my left hip was throbbing. The pain was mild, it was more like intense awareness of those areas, down to my toes. At some point he led me through a visualization, using the breath to go into the center of the pain and filling it with love and light. I spontaneously imagined a fire, and the smoke rising from it. It was wonderful. The sensations changed into something spacious and blissful.

Afterwards he said the ceremony lasted about two hours, which I found astonishing. He said part of the purpose of this disease is for me to show people how to handle death. He also said there was kind of a blockage in my throat, that I need to be very vocal in expressing my needs during this time. I wasn't quite sure what that meant but

perhaps that will emerge later. He said he communicated with an owl, and that there are protectors or guardians around me.

We talked about death and I was telling him how impressed I am by him having found his vocation, and his commitment to helping people heal. By the end of the session we were both crying. He said he would be there for me on my journey. It was incredibly comforting.

January 10: **Non-benefits of having cancer**

Here are two things that, at the moment, don't appear to be benefits of having cancer. As you can see, they're both about other people!

1. When someone seems to think that they know why you got cancer – it's definitely because of something you did. They're sure it's the type of food you tended to eat, or some poisonous thoughts you had. Which isn't to say that these things couldn't have been a factor. (I am resisting the temptation to show that for me they were not.) But there are also other possibilities – genetic, environmental – and no doubt others we know not of. My working theory is that imbalances in my body caused by perimenopause – depletion, depression, losing a lot of blood – were a factor. At the end of the day, I have no idea why I got cancer. Five oncologists don't know why I got cancer. Does it have to be my fault?

2. People who want to help you so they tell you (or write books that say) that you can cure your own advanced stage cancer - by drinking vegetable juices, eating turmeric, singing, being vegan, or drinking diluted hydrogen peroxide. (I'm exaggerating, but not much.)

Alternatively, that you should forgo chemotherapy etc., which is what will really kill you. Certain foods are bad for cancer patients. Those same foods, claims someone else, are good for cancer patients. It has been confusing. However I have mostly chosen my path: Chinese medicine according to Misha Cohen, diet and other lifestyle recommendations from oncologist Dr A (plus leaning toward foods that are more alkaline), and my health plan for chemotherapy and radiation.

So these are the things that are difficult. Also, it can be very painful for me when friends are upset and crying. The fact is that I feel very strongly that I have to be prepared to die. In a way this is what keeps me from being depressed every day. However, I don't mean to suggest that that is some kind of precognition, or that other outcomes are not possible. Think of the Sting song, 'If You Love Someone, Set Them Free'. But the someone is your life.

January 11: **MRI**

Rather than a donut (CT scan), the **MRI** is a tube, and while inside it I immediately understood why they ask beforehand if you're claustrophobic. And there are a lot of rapid banging sounds in varying pitches. (They gave me earplugs.) After around half an hour they took me out, shot me up with a dye of some kind, then put me back in for about 15 minutes. It was kind of hot inside that machine, I was wearing too many layers, but I felt very relaxed by the end. Then I got slightly lost trying to get out of there, a bright red EXIT sign gracing every corridor. Even tried to take the stairs but I could see that after

the down stairs, they just went right back up again. A kind man told me how to get out of there – and eventually, ah, outside.

“Sugar Feeds Cancer”

Quote from Dr A: “Tumors are gluttons for glucose. They consume this blood sugar at a rate of ten to fifty times higher than normal tissues.” This reminded me that a couple of months ago I went to [Community Acupuncture Works](#) (a lovely place and very affordable) and I remember telling Ninah that I was having intense sugar craving. She asked if I had had this before. I said I didn’t think I had to this degree.

So this is maybe related to “sugar feeds cancer”. I would add, Feeding a sugar craving feeds the sugar craving. Of course this is probably true of any kind of craving. If you indulge it, it may come back stronger. I have virtually no desire to eat anything with added sugar now, and less craving for fruit. Not because I know that sugar is bad for me, but because after I stopped eating it for a day or two, I lost interest. I’m really grateful for this actually, that it’s not a struggle.

Radiation 101

Padmatara, Julie, Pasadini, Dawn and I went to a “Radiation 101” class today. We saw the unbelievably sophisticated and huge machine made by a local company which delivers radiation; then there was a slide show with several different people talking about their areas, including a Medical Dosimetrist, a behind the scenes guy who “designs a treatment plan by means of computer and/or manual

computation to determine a treatment field technique that will deliver the prescribed radiation dose while taking into consideration the dose-limiting structures”.

A nutritionist spoke for a bit. Looked at the booklet [Eating Hints: Before, During and After Cancer Treatment](#). Some of it was to do with managing side effects of treatment, but... for example, I can't believe they tell people losing their appetite to drink fruit punch! I'm much more confident getting nutritional advice from the acupuncturist, who says to eat omega 3s, all organic food, very different.

A social worker told us some interesting stuff – I will give her a call at some point to find out about classes for people with cancer and support groups. Would also like to go to the “Look Good... .Feel Better” class offered there by the [American Cancer Society](#). They tell you how to draw eyebrows and other cosmetic stuff. It had only vaguely occurred to me that I won't have any eyebrows, which almost seems worse than losing the hair on my head... It was nice to be there with friends. It did possibly make it less scary.

January 12: **A different diagnosis**

Here is my diagnosis from Misha Cohen's office: Yin and Blood (Xue) deficiency with lack of Qi in Upper Jiao, Kidney and Spleen Deficiency, Heart Fire, Toxic Heat, Chong Mai Imbalance. Doesn't sound too bad, does it? Well, sounds better than Stage IV cancer, I would say. Anyway the treatment plan is 5 pages, and they want to see me 2x/

week during chemo. There are a lot of nutritional recommendations which I want to follow...

January 13: **Optimism or pessimism?**

Here is some of what I've been reading, written by the oncologist Dr A, who has worked with many, many people with cancer:

Bombarded with doom-and-gloom statistics, you may feel overwhelmed trying to muster enthusiasm for life. So forget all the talk of 'survival rates'. They do not apply to you. All statistics, by definition, apply only to groups, not individuals. Researchers use them to determine whether a therapy works or not, and physicians use them to help make choices among different therapies. But as an empowered individual, you should not use statistics to dictate your chances of survival.

I don't really have any statistics to deal with, yet I find this very sensible and encouraging. It doesn't mean that you know you're going to live, it doesn't mean that you know you're going to die – it means you don't know what will happen. And how incredibly difficult it is, to deeply not know, to be neither optimistic nor pessimistic, when there is no objective cause for either. What you do know is that you cannot control the outcome, and that what you do will have some influence. Anything can happen.

January 14: **A walk at Spooner Lake**

It is lovely to be up here in Tahoe. Went for a hike with Mike and Dawn around Spooner Lake. In the bright sun the aspens near the shore

were particularly beautiful. We saw a bald eagle flying close to the surface of the water. Eventually it flew right by us, amazing to see.

Last night I felt some pain in my pelvic bone and hip joints. I'm wondering whether my days of not having any pain are over! It might be from sitting in the car for hours, and in fact the last time I felt it was up in Lake County, also after a long drive. Also I haven't worked out the challenge of how to sit in meditation. I was realizing today that it's probably more painful because of what I think. It's not just a sensation, it's the thought of cancer. I'm pretty sure this thought makes the pain seem worse. So this is my next (mental) project, to try not to add to the physical pain with my mind. The doctors say that once treatment starts, it will help with the pain...

January 15: **Whale Beach**

Wonderful walk today, from the east side of Lake Tahoe in Nevada, down a wide path of towering and gnarly western red cedars. We landed in a beautiful little cove called Whale Beach. There was no one else there. We stayed for an hour or two. Toward the end of the afternoon the wind started picking up and the waves were crashing and spraying in the sun. My sit bones seem to ache a little more every day. Pillows are my friends. Walking is one of my favorite things to do... it doesn't seem to affect the pain either way. It was not a long walk, but it is a high elevation (6,000 or 7,000 feet I think), and it was a lot of sun, and a lot of cold wind. We were all completely knackered when we got back.

We had an excellent dinner and everybody went to bed. Time for me to do that too. Sorry for the abject lack of philosophical content. I'm feeling depressed at the moment about how my life might be for the next... however long. But I don't want to write about that so much.

January 16: **Lying on tables and other gifts**

I've lain on two tables today. One at the acupuncturist's, and one for a radiation simulation, which involved being jacked up to around shoulder height, and watching all these crazy mechanical arms and other gizmos circling around my pelvis for around 20 minutes.

I tried to get a short haircut today, but the stylist had called in sick. The other one I tried was on vacation. Will try again at Grasshopper in South Park, 3pm Thursday. If that doesn't work, screw it – I'll just wait for it to fall out!

I signed some papers about State Disability, and getting a Handicapped parking placard (no, you can't borrow it!) Still need to get my car registered, get an area parking permit, and sort out some other parking for the next while. Also I'm almost done changing the beneficiaries on my IRA which has taken a while because I need people's social security numbers. Am also doing an Advance Health Care Directive. So much paperwork! Also trying to de-clutter my living space a bit. I was told yet again today that side effects won't kick in for about two weeks. I hope it's true so I can get some more stuff done.

Felt very loving toward the people on the BART train again, especially the man with the very strong accent of some kind who asked me which train platform goes to Embarcadero (but pronounced it in a way I could barely understand), and then which train. He was with his son. I felt very protective of them.

I have received many gifts. People have given me money, which is such an enormous relief, not to mention books, a car, loving emails, cans of sustainably farmed tuna, groovy socks, company, nutritional solidarity, books, rides, good vibes, and salads at Fresh Choice. And there is the gift that I maybe understand a tiny bit more about the Buddha's teachings on impermanence...

January 18: **The movies I picked were crap (Chemotherapy)**

I felt nothing unusual when I was getting it injected into my hand. It took about three hours – an hour of hydration (water with sodium and magnesium), an hour of cisplatin, and another hour of hydration. I also felt nothing during radiation this morning. In bed now, feel slightly nauseated whenever I get up – have meds for that. It's the main side effect. No more nausea after I rested for a couple of hours. I'm still going to be taking two different anti things for three days, so we'll see. The sweet radiation oncologist Dr O told me today that the radiation would very likely stop the bleeding and decrease the pain in my sit bones.

Appointment tomorrow @ 2pm for the ever elusive haircut. Was pondering a Michelle Williams do. Don't know if I can face a pixie.

I'm very glad the treatment has started. Let's get this shit done!

January 20: **Another day**

Day 3 of radiation, then PT and I drove in the rain to the San Mateo DMV. I got a temporary handicapped placard, and registered my car, which I am getting tomorrow. My sister Laura and her husband are driving it over from Fresno and taking the train back. Because the chemo I am getting is primarily a 'radio enhancer', meaning its main purpose is to enhance the effects of the radiation, I am getting a lower dosage than someone would who is just getting chemo. Thanks to that, the real trouble isn't supposed to start for another ten days or so.

Had a wonderful acupuncture treatment last night. Beforehand my lower gut felt like it was tied in a knot and I was having little waves of something like motion sickness from standing up. The other times I've gotten acupuncture there I felt the needles very intensely. This time, all I felt was a slight pain in my lower abdomen. She said she was going to work on the nausea, and circulating the chemotherapy drug. It felt like that's what it was doing! I fell into a deep, completely absorbed and restful sleep during the first part of the treatment. I am so grateful that I am able to do this.

Saying that I wouldn't have gotten the haircut if I didn't have cancer might have implied I don't like it. I love it! And I'm a dyke magnet now which I might as well enjoy (even though I'm a celibate heterosexual with a very messed up vagina!!) (It must be said.)

How Can Cancer At Least Occasionally Seem Like Such a Positive Thing? I wrote a while back about sitting in meditation, tuning into the tenderness in my heart. I am acutely aware of this now, not only of my own tenderness, but of being surrounded by it. Like my need to defend or protect myself has somehow broken down.

A few people have told me that it was upsetting to read that I am thinking about being ready to die. It is understandable. Being ready to die is also an extremely positive thing, because being prepared for death is essentially the same as being ready to live. You can't only be ready for one thing, they are too much inside of each other.

My life has become more unified. I realize how often in the past I have felt subtle guilt about what I am doing (or not doing), or subtle anxiety (often about money, about the future). I have spent so much time planning, planning tomorrow, planning next year. Now, I can't think about anything more than two weeks away. Really: nothing. I do not think about the future. It is too clear that there is nothing I can know about it right now.

I do not feel that I am practicing, or trying to do, anything, but certain things have dropped away or simplified in ways I could not have anticipated. I feel less psychologically complex. I feel that what I've been practicing (or something) has flowered... into a caring and connected feeling for friends and strangers around me. For example, on the street I spend ages petting a dog, or chatting with an at least slightly crazed homeless person. The world, the life that the world is

filled with, seems magic. I don't think I have ever known so deeply that I am loved.

If my life returns... Well, could my life ever return to what it was? Doubtful. But if someday I am able to expend some energy in other ways, through somehow to the other side of cancer, I hope some part of these threads, which have made my life so sweet, will carry on.

January 23: **Life/A giraffe is very large**

I thought I knew how big a giraffe is, until I stood next to one in a forest. My head did not reach to the top of his leg. You could stand underneath his stomach, I mean, if you felt like it, but you probably wouldn't feel like it. I'm 5'9". It's like looking up at a big furry house that walks. Then the giraffe isn't there anymore, because five years have passed, and that was in another country. But still: we are small. We are a dot. We can barely stand up beside the stature of anything, even our own body, which is in some way king of it all.

Today and yesterday, my guts are in painful turmoil and I am very tired. Has it really only been four days of treatment?

If you are divided from your body, you are divided from the body of the world, which then appears to be other than you, or separate from you, rather than the living continuum in which you belong.

Phillip Shepherd

Last night I saw Misha. She mentioned working with the FDA and doing trials of herbal lotions – something to do with HPV and cancer. Then she put in the needles, I don't know, maybe 20, mostly in my head, lower abdomen, and a couple in my feet or lower legs. She said she was working on 'stabilization' and releasing dead cells from the body. And I lie there for some indeterminate amount of time which does not seem long. Then someone comes in and stimulates certain points with a burning cigarette (not really, but it's a burning ember and it smells good). It feels fantastic. It's called moxa. When I was lying there I was thinking, this is the only time I do not feel sick, the only time I feel very deeply well. In fact the only time I can feel energy moving through my body, and at the same time I feel deeply calm, is when I am there. It's the only time I can fully relax. I feel a lot of confidence in my western doctors, but I feel that what they are covering is a narrow band of my life. Going to Misha fills in everything else.

A couple of friends have suggested I get a second opinion about my treatment. A Buddhist here who is a doctor has put me in touch with a specialist at UCSF, Dr C. I have felt on the edge of not quite being proactive enough to go this far, to add to all the appointments I have. But I am doing it. Today I got all my paperwork in to get records forwarded. They will call me for an appointment when they get the records.

I filled out an [Advance Healthcare Directive](#) yesterday with Dawn and a talkative bald cancer patient as witnesses. You know, don't keep me

alive as a vegetable; when I'm dead I want everyone to get drunk and sing 'Spirit in the Sky', etc.

January 26: **A nun flies through the chemotherapy room**

Yesterday: First, radiation, and a chat with my main oncologist, Dr O, with Karunadevi and Julie. He said the treatment is going well, which as far as I can tell means that nothing has going wrong! (There are no diagnostic tests during this treatment phase.) In response to gut turmoil he suggested increasing fiber, and avoiding eating raw fruits and veg. He also said there's a possibility I will become lactose intolerant during treatment. Karunadevi suggested probiotics, and he agreed that was a good idea. (It's funny how my doctors never seem to volunteer this kind of info first!)

During chemo Julie and I watched the first episode of **The Flying Nun**, which will only register with Americans over a certain age. It's about a nun (Sally Field about 2 years old) in San Juan, Puerto Rico, who, because of her wing-ish headgear and very small frame, flies. And Ricardo Montalban and a nun who reminds me of my friend Kitty. We also watched the documentary '**Crazy, Sexy Cancer**'. I liked it – interesting to watch someone else's journey. Made me realize too how people think – and a month ago I thought – that cancer is all kind of the same deal. But this lady had 14 tumors on her liver and lungs that, eventually (spoiler alert as they say) were just sitting there not doing anything. Which is as close as she can get to being cured – nothing to do but check on it once a year.

Individual cancers, just like people, can have totally different personalities! Grow at drastically different rates, respond to different treatments. Even what doctors look for – what is a good sign, what is a bad sign, what is a perplexing sign – seems to depend on what body part/s and what kind of cell within that body part. For example, an oncologist said he was not concerned with how big my tumor is. How deeply it has penetrated into the tissue is what is significant. I'm not sure what mine's personality is. We'll have to see how it responds to what Dr A called the 'attack phase' of treatment.

Speaking of cancers being different, as you might imagine, vaginal cancer cannot be called sexy. Not that I've ever seen it what it looks like (that would be trippy), and I've had virtually no vaginal pain... but still, sexy? My movie would be called *The Crazy Antichrist of Sexy*. Presumably the title works for the woman who made the film, who is a successful actress in NYC and ends up getting married. My sex is what has cancer, so that's very different, it probably goes without saying. Anyway.

January 28: **Sisters and perspectives**

Had a nice conversation over Skype with my three sisters – well, two of them – last night. Laura, who is the closest geographically, kept getting dropped. Cull and Po are both into exploring life, exploring experience with honesty and humor. Both have been involved in [Codependents Anonymous](#) for a couple of years. At one point Kathy asked me if my vagina is going to be like Auschwitz. It was very funny.

I was thinking – In what sense? Not open to visitors? Or you can check in, but you can't check out? I forgot to ask.

We talked a bit about working with positive affirmations. I had had an interesting experience noticing thoughts that day. I noticed that when I felt bad, I would think about how bad I felt, and it would make it seem worse. Then later I noticed that when I feel good, I think that I am – and there is something about how I was thinking of it that is not helpful. Kathy suggested that maybe it was because how I was thinking about it was a barrier to the direct experience, and I think this is true. There certainly is a way to evaluate that is both necessary and useful. But then there is something that has, from my Buddhist perspective, a feeling of... stickiness. Which is as subtle as the difference between “This is how it is right now” and “This is how it is.”

In general, I'm doing very well so far. This week after chemo I felt better than I did last week – that was a shocker. I attribute my wellness to lots of complementary medicine: acupuncture twice a week (day before and after chemo), healthy food, walking every day, naps, not having to work, no sugar or caffeine, quarts of hydrating coconut water, and later today, a massage that Tong got me. Yay! It can also change quickly. Nausea/motion sickness/gut wrenching never feel far away...

January 31: **Impact of blueberries**

Very tired today. Have been lying on my bed watching movies for hours. Now I am eating excellent blueberries which are from Chile.

That's part of what's wrong with things, I think, that someone in San Francisco in January can eat a big thing of organic blueberries for \$4.99, flown all the way from Chile. That is almost 6,000 miles from here. Also, the eight different kinds of coconut water at Walgreens. Where are the coconuts from? Is there a mountain of cracked coconuts on a beach somewhere? How far do they, or the cans, travel?

It's interesting: what one thinks one is owed, or deserves, or maybe just what one is unwilling to give up, given a choice. You might say, well, she has stage IV cancer, why not have a few Chilean blueberries? I don't mean to labor the point, but I feel that the sense of entitlement – or perhaps it's just an inner sense of lack – that millions of us have, is what is heating up the earth, which will some day make it uninhabitable. (Not to oversimplify, or to claim all the responsibility!) My life is fricking easy, and compared to the kind of hardships that are available in life, it always has been. Sure, I may be dying of cancer, but even if so, that's been pretty easy so far.

When I am at the acupuncturist, I visualize white light filling my body. My lower abdomen often feels dark. A couple of nights ago I had a dream about watching a show in an old, cavernous theater, trying to get out quietly before it was over, which was tricky. There was a pitch-black room at the bottom of a huge staircase, so you had to turn on the light at the top of the stairs before descending.

My friend in London ordered this poem for me at 'The Poetry Takeaway' at the Festival for the Living. She says: "I told a rather nice young man a very little bit about you and your cancer, and an hour later went back and he read this poem aloud. Given that he had two others to do before mine I think it's pretty good... In fact I even felt quite emotional when he read it. Not a masterpiece, but good enough to send you, and I really thought you should have it. Interestingly, I didn't mention that you are musical (or indeed that you write some pretty good poems yourself)."

Four Words

Cancer of the vagina

Four words that could deflate even the most
inspired of erections

Four words I want to whisper in the ear of a rapist

Four words I want printed in white block capitals
on a skin tight vest

Four words to shout from a mountain made
entirely from cancerous breasts

This is the opposite of testicular cancer

Cancer – the word that rhymes with dancer

I've got music coming from my vagina

Dance with me

Bodies really hurt!

from an article, 'Tearing open the dark', August 2008

I remembered a meditation experience from a group retreat many years before: for a few minutes, my body turned into light, was poised with its 'foot' in a position of stepping out, as in a statue of Green Tara. I couldn't sustain this god's body, and my awareness would come back into the body I am more familiar with, a painful transition. It was like falling down, back into solid form. And I could see, I could feel, how painful it is just to have a body like this. My awareness went back and forth a few times, between being a radiant mist-of-light and being in this, more substantial form. It was an amazing experience, and I remember thinking that, relatively speaking, wow, bodies really hurt!

February 12: Paulette: “I felt like I was a part of something really special, something incredibly loving and kind. It didn’t matter that I couldn’t understand the words...”



February 2012: What can I tell my bones?

February 1: **Hostile takeover of abdomen**

I guess they weren't kidding when they said the effects of radiation take a couple of weeks to kick in. The last couple of nights, I got up eight or ten times during the night to pee. It's as if my lower abdomen were suddenly taken over by hostile aliens who cut off the water supply.

The oncology nurse made various product suggestions. They want there to be as little medication as possible (interferes/interacts with chemo). I'm meeting with Dr O today, will see what he says. I know sometimes they stop radiation for a few days in the case of really bad side effects. Don't know if mine are going to rate, since I don't have any infections. Misha gave me some herbs to take and as usual I felt so much better after seeing her. She was emphatic about eating more protein every day and suggested the section, "The Treatment Support Diet" from Life Over Cancer.

Medical marathon...

Went for radiation at 8am, and an exam with Dr O. Turns out the state of my dryness and irritation thus far is 'normal'. He gave me some medication that will prevent me from waking up so many times at night to pee, and he put in the system some other medications and tests should an infection develop. Realized later that I was a bit

panicky when I talked to him. He mentioned that they only stop radiation rarely, that it has to be done sometimes but to consider that since it allows the healthy tissue to heal some, it's also going to allow the cancer to heal (or anyway, to grow). In other words, even though I think I want a break from the radiation, I really don't! The radiation is most effective when it is steady.

Then Pasadini and I drove in a lot of traffic down to Geary St. for chemo. C (oncology nurse) was telling us very funny stories – he was very entertaining! I also really trust him. And Tong stopped by for a chat. We didn't watch any movies, I kind of have movie burnout, though we did have the private room with the nice view! I do need an entertaining book to read. [Bossypants](#) was a tough act to follow. C also said my weekly blood tests are very good – he described them as 'abnormally normal'. He said after the third week is often when hair starts thinning...

Met with Dr J, who is filling in for Dr S, who kind of vanished without telling anyone why. (C, Pasadini and I determined that he is either in rehab or has contracted some big-time STD.) I will meet with him at the end of treatment, to find out the truth no doubt. Anyway I mentioned to Dr J that I am getting acupuncture twice a week and she encouraged me to continue!

Walked around the Mission doing some medical type errands and felt pretty wrecked afterwards. (Still, it's good for me to walk around, and I like it.) I feel emotionally fine, just very drained. Apparently I started

looking very pale during chemo. But I'm all right on the inside somewhere.

On the phone on Valencia Street, I told a friend that I no longer have a vagina. What I have now is vagina jerky. (I hope that my kind readers will realize that this is a gross exaggeration. Really it's more like the sushi in that place where the sushi sails around on boats until someone picks it up, but some of them circle around too long and start looking all dry and nasty. Next time it comes around, it has sauce on it, which is also what I am trying to do. And I want to tell you that inventing humorous or any other kind of description of my vagina isn't a usual pastime. I just can't stop myself! I do at least amuse myself...)

But as long as I'm at it... my friend offered the helpful suggestion that I come up with a name for my vagina. Someone tonight suggested Flo, as in the southern waitress type, and then realized her error. It was very funny. I was thinking something like Hyacinth McMullen. In addition to the many excellent qualities of this name, it is also apparently the name of a deceased Catholic nun. I like irony, folks, and also claiming things are ironic that possibly aren't.

Lay down on my bed for a little while then spent ages putting pills in new dispenser. Was pondering elderly people, who take all kinds of medication, and how hard it must be for them to get it right. Taking things at certain times for a certain number of days, with or without food and with or without other medications, and not taking them all at the same time. There is something about my cognitive function that

has kind of lowered this last month or so. I very much enjoy writing but sometimes in conversations it seems that I am easily confused.

February 2: **A late night**

My various symptoms seem much better. The acupuncturists today were very happy with how great my blood counts are etc. I feel so good when I am there. Was wide awake until about 3am this morning and didn't know why. Read the sheet that came with the Chinese herbs (called 'Marrow Plus') I started taking. Apparently some people get a lot of energy from astragalus, some do not. I know which one I am – and that I'm not taking it at night anymore! Laura arrived tonight, chauffeured by Ben from the Amtrak station in Emeryville. I felt very healthy today – but it's going to be a relief not to have to keep track of stuff so much!

February 3: **Three poems**

from **What Can I Tell My Bones?**

by Theodore Roethke

Mist alters the rocks. What can I tell my bones?

My desire's a wind trapped in a cave.

The spirit declares itself to these rocks.

I'm a small stone, loose in the shale.

Love is my wound...

Instead of a devil with horns, I prefer a serpent with scales;

In temptation, I rarely seek counsel;

A prisoner of smells, I would rather eat than pray.

I'm released from the dreary dance of opposites.

The wind rocks with my wish; the rain shields me;

I live in light's extreme; I stretch in all directions;

Sometimes I think I'm several...

O to be delivered from the rational into the realm of pure song.

Cancer Cells

by Harold Pinter

“Cancer cells are those which have forgotten how to die”

(Nurse, Royal Marsden Hospital)

They have forgotten how to die

And so extend their killing life.

I and my tumour dearly fight.

Let's hope a double death is out.

I need to see my tumour dead

A tumour which forgets to die

But plans to murder me instead.

But I remember how to die

Though all my witnesses are dead.

But I remember what they said

Of tumours which would render them

As blind and dumb as they had been

Before the birth of that disease

Which brought the tumour into play.

The black cells will dry up and die

Or sing with joy and have their way.
They breed so quietly night and day,
You never know, they never say.

Cell

by Margaret Atwood

Now look objectively. You have to
admit the cancer cell is beautiful.
If it were a flower, you'd say, How pretty,
with its mauve centre and pink petals

or if a cover for a pulpy thirties
sci-fi magazine, How striking;
as an alien, a success,
all purple eye and jelly tentacles
and spines, or are they gills,
creeping around on granular Martian
dirt red as the inside of the body,

while its tender walls
expand and burst, its spores
scatter elsewhere, take root, like money,
drifting like a fiction or
miasma in and out of people's
brains, digging themselves
industriously in. The lab technician

says, It has forgotten
how to die. But why remember? All it wants is more
amnesia. More life, and more abundantly. To take
more. To eat more. To replicate itself. To keep on
doing those things forever. Such desires
are not unknown. Look in the mirror.

February 5: **Too much excitement**

I feel deeply tired and nauseated, and my nether region continues to feel like ground glass. I am nervous about Wednesday, which is when I go for chemotherapy at 8am, then drive straight down to Santa Clara (over an hour's drive) for my first session of brachytherapy, also known as internal radiotherapy, which starts with spinal sedation.

Went to a class today offered by volunteers for the American Cancer Society. It's called Look Good... Feel Better. It's pretty much tips and tricks for dealing with not having any hair, eyelashes, or eyebrows. Plus a bag of free donated makeup. Some of the class was fun. It was two hours long, however – too long for me. By the last ten minutes, I went dead pale and was worried I might pass out.

February 6: **More pain**

Got a call last night asking if I wanted an appointment with Dr C at UCSF this morning at 8am. My records have already been forwarded to her. We met with her and, in short, she said she would treat me in exactly the way I am being treated. This is based on data from studies on cervical cancer, which acts similarly to what I have. (What I have is too rare to do a study on.) She did an exam and said it seemed that the radiation was working (as much as she could say, not having seen the tumor before). She said the radiation keeps working after treatment stops. In other words, the tumor continues to die and the body absorbs the dead cells.

Laura asked when the post-treatment assessment happens. She said they usually do a CT scan a month after treatment ends. But because of inflammatory changes as the tumor dies, it can mess up a PET scan, so three months is the amount of time for the PET scan. This brings up all kinds of issues about medical insurance and where I can live. But I will think about that later. She also said my staging was 4B (the highest stage you can get.) The doctors at my health plan never specified. This was possibly more upsetting for Laura than for me. I've kind of heard it all (even if I haven't heard it!)

Anyway I'm glad we met her, though it will mean more pain after the exam (the normal thing would be not to do an exam during treatment partly because it's too painful). I didn't really have any doubts about my doctors but lots of other people thought it was a good idea. It was nice to talk to women doctors.

February 8: **Utter contentment**

Yesterday when I was with Misha, I thought, she's going to stop liking me. I thought I might have been a little whiney about things. (Something similar today with C, the oncology/chemo nurse.) A flash of the thought, Oh dear I am such a needy bastard in pain today, all kinds a pain... After the acupuncture and going to a chi gung class afterwards, I felt much better on all levels. Some of you are members of the Needy Bastards fellowship, in which case you might get this more.

While lying there with the needles, I kind of moved away from visualizing light... Because of the radiation I think, which now that I think of it is essentially light, the sun being the major source of radiation. In any case, light feels too... dry, or hot. So I changed to something more watery, more earthy, smokey.

After chemo today, drove down to Santa Clara for internal radiotherapy. Suffice it to say, the fear was misplaced. It was the best thing ever! Why? Well, during most of the four and a half hours I was there, my body was super-relaxed, a state it has not been in for a long time. I felt no pain (also, been a while). I felt utter contentment. Mentally, I went through everyone I could think of and said "I love you". At the same time, I felt very lucid. In short, I was doped up, but felt incredibly awake and happy.

I had all sorts of things attached to me and tubes all over the place. Three electrode things on my chest to get heart rate, a blood pressure thing on my arm that automatically checked it/inflated every 5 minutes, a weird red neon thing on an index finger to check oxygen absorption, a catheter, a tube thing across my nose measuring CO2 (which I think means it's just checking to see if I'm exhaling, that is, breathing). They all seemed surprised (there were 5 or 7 people around a lot of the time) when I would reply to things, and had my eyes open. They told me I wouldn't remember anything, but I think I remember everything. There were panels on the ceiling that reminded me of lying on the bench at Camp Double Bear and looking up at the sky.

However, even after spending 45 minutes in a chill out room, I couldn't walk. But by George I was in an excellent mood. My pelvis and possibly more importantly my feet were completely numb. Laura pulled up in front and the awesome nurse wheeled me out and managed to get me into the car seat. We proceeded to get take-out Chinese food (I hadn't eaten since the previous night) and eat it in the car (I couldn't get out of the car). By the time we were back in San Francisco I could walk. It took a bit longer to wear off than they warned me about.

The radiotherapy dosage today was the equivalent to what I get in a week of external radiotherapy. The device they used to administer it looked like some kind of medieval torture device, covered with blood. It involved 14 long hollow needles, which were delivering high dose radiation via things that looked like wires, directly into the tumor. The length of each wire changes during the nine minutes of treatment. They were mostly invading the tumor which doesn't actually have any nerve endings/feeling, so this was apparently less invasive than a normal exam. But a lot of blood and piss are flowing from me now (I was warned about this), as the pain returns. The feeling of ground glass seems to alternate between three adjacent apertures. Must talk to Dr O about that tomorrow. Still, it was somehow a very positive experience!

February 10: **Meeting with Dr O**

The cute and communicative Dr O told us that cisplatin, the chemotherapy drug I am on, isn't necessarily associated with hair

loss. That was a surprise, showing again how cancers are different, chemos are different, treatments are different. He said my immune function is not seriously low. My magnesium & calcium counts are high, my kidney function is very good, and I haven't had any side effects from the chemo except nausea. My blood counts have gone down a lot but are still within healthy range. I think I said somewhere that my dosage of the chemotherapy drug is low – he said today that it isn't. It's the maximum dosage for when it's combined with radiation. (When it's not combined, it's a higher dosage given less often.)

I forgot to say about the radiation treatment that they (necessarily) punctured my bladder. Also, after the treatment is over, especially if the tumor is eliminated, I may end up with a tumor-sized hole inside me. Hopefully, it will heal on its own, but could take several months. These ideas don't bother me nearly as much as they did the first time I heard them.

Another thing we talked about is the post-treatment timeline. I guess I had this idea that on date x I would know what my situation is. But it doesn't seem to work like that. After a month I get a CT scan, after three months I get a PET scan. Then there will be a lot more info, but still it all seems somewhat provisional. It's a See What Happens kind of situation.

February 13: **Le weekend**

It seemed to me that there were a lot of people at the ritual at the Buddhist Center on Saturday and I felt a bit overwhelmed and weepy for a

while. We chanted the Aksobhya mantra (with some bells and a drum that sounds like the ocean), which to me meant cooling water and blue light. It was very beautiful. Then we did a little guided meditation and ended with the Heart Sutra and the gate mantra with offerings of lights and beautiful orchids. I was able to sit in my normal meditation posture the whole time without pain, which was fantastic. Afterwards Padmatara, Pasadini and my sisters made Vietnamese spring rolls and we all had dinner downstairs with Shantinayaka and Elaine, then watched two episodes of Nurse Jackie.

Saturday night was tough. Woke up many times in pain. I'd felt enthused about vicodin, but taking it makes me a little nervous. Had a good conversation with Danamaya, who said it takes 4 to 6 weeks of daily use to become habituated.

February 14: **What is "Suva"? And music, or what passes for it**

Someone mentioned that they figured "SuVa" was short for "Suvanna's Vagina". Of course that works for the current situation, but to clarify my intention, Suva is simply a shortest version of my Order name. Other people seem to favor Suv or Sue, both of which grind on my ears for some reason. Suvy worst of all. Of course they're all wrong, including Suvanna. The name I was given when I was ordained in Tuscany in 2001 is Suvarnaprabha, which means "Golden Radiance" in Sanskrit. My attempts to simplify it for Western people (who tend to go cross-eyed when they hear a five syllable Sanskrit name) has probably made it more complicated. But that's not what I was planning on writing about.

Although I have what is called 'primary vaginal cancer', my subjective experience is not so much about the vagina anymore. The vagina is simply the provocateuse. Now the situation is more like a sad trio crammed together and forced to play in a hot and airless cupboard. There is a tuba, a piccolo, and a violin. Strings are broken, tuners are lost. The musicians have not had a drink of water for a very long time. They each continue to try to fulfil their designated function.

Lesson: If possible, do not take your piccolo for granted, or the breath that drives it. My body now seems to require an enormous amount of symptom and pain management. Shitting and peeing cause a level of physical trauma. (In the past I have used the word trauma rather lightly.) (I also usually have many hours per day with no pain, it varies a lot.)

February 15: **Things weren't as trippy as last time**

I sort of like getting the internal radiation. I think the reason I like it is that, while I know what they are doing is pumping a large amount of radiation into my body via needles, the actual experience of being there, no doubt because of the drugs, is relaxing. It's also relaxing when the drugs wear off. It really does not have the side effects that the external has.

The Indian woman anesthesiologist didn't dope me up as much as the Russian man last week, which was fine. Although those in the radiation room had to endure much more silence this week than last, poor things. From my point of view, things were a lot less trippy-

looking. Just another room – this one no doubt with lead walls – full of men (some of them wearing ties!) and women with my vag, doing stuff that blissfully I cannot feel. Met the physicist who is apparently kingpin of it all. They are all really nice people. When Julie and I were talking to the nurse, Dr L came in and said hello and asked how I got on last week. I love him, and this proves that it's not just the drugs (since I loved him before the shot in the spine).

Padmatara and I are not really good chemotherapy tourists any more, taking pictures etc. as if for first time on a foggy cable car ride. Good egg salad sandwiches though from the cafe, a visit with Tong, and a few episodes of [Nurse Jackie](#)...

An excellent forced march with Shantinayaka. Who forced it? I did, I asked Pasadini to put it on the helping calendar. With the radiation thingy yesterday and chemo today, I've pretty much been on my back, or sitting in a car or chair, the last two days. So I pried myself up and we went for a walk up the hill past Dolores Park and back and I felt so much better and energetic afterwards. Most of the chat was about dire medical situations. Note to self: Must expand conversation topics.

Food preferences have shifted toward liquid – soup and protein/fruit shakes (especially raspberries lately, so good!) I still eat and enjoy other things of course (like Cameo cheese, yum!, and crackers) but find liquids much more straightforward for digestion.

Up until the day of my diagnosis I was planning on leaving San Francisco in a few months, probably to New York City for a while and then to West London if that became possible. I haven't really gotten my mind around the fact that if I leave San Francisco I will not be able to get health insurance, which effectively means that I cannot leave San Francisco. Unless Obama's "The Patient Protection and Affordable Care Act" actually happens, which is hard to imagine.

February 16: **A terrible clam**

I will be on retreat until Tuesday, yay! Packing is kind of challenging since I am knackered and have half a brain. Had a rough night last night – couldn't sleep until about 4am and very very itchy. My body full of tension. However, today, no pain, no itching, felt pretty good. Condition subject to change.

Had fluffy cornmeal pancakes for breakfast. With syrup! That's what I call splashing out. Also found out you can't bring Quorn sausages (if you don't know what they are, never mind, you're better off) from England to the U.S. without risking a \$10,000 fine. This is a great tragedy.

The docs say my tumor is shrinking. Misha felt my pulse today – which in Chinese medicine is three fingers on the edge of your wrist, not about blood pressure – and said my 'tumor pulse' was very different, I believe she said much weaker. I hadn't told her what the doctors said. So that's good. I hope, obviously I guess, that the tumor is gone after three months, and I don't have to do any more treatment. Cancer

treatment, at least at the point I'm getting to now, doesn't leave you with much of a life.

Dr O clarified more about the immunity thing. Apparently chemo patients can get very susceptible to really bad infections, pneumonia, etc., just from catching a cold. He said my level is that I might be slightly more prone to catching someone's regular cold.

Did manage to meditate today which was great. I really love meditation, it's amazing that I have pretty much dropped the ball on it. I do a lot of mindfulness practice and reflection, but now feel the need for the formal stuff too, especially enjoying sitting on the floor again.

Oh yes, I remembered what I was going to write about. My friend said when she witnessed a woman giving birth, that the woman commented that her vagina looked like a "terrible clam". I know how she felt.

February 21: **A weekend retreat + medical Fat Tuesday**

Day 3 of retreat

Being on retreat is wonderful, and also difficult. Sleeping 15 or so hours a day/night, and much of the food is not right for me (forgot to give guidelines for food). Of course I never know for certain the causes. I was lying down in my room and couldn't stand up without almost passing out, so waited a couple of hours before I could stand up and walk outside. Danamaya came back with me and was very helpful as always.

Day 4, 10am

Feel shaky, weak, and moving slowly. Dosed up on zofran and decadron to prepare for the ride to Redwood City for blood test today. I had some other observations about the retreat but I'm too tired to recall them. Did have a cool dream yesterday about a huge house way up in a huge tree.

I was trying to think of what the cumulative effect of radiation feels like. You don't feel anything when getting the treatment – it's like the sun. You can lie in the sun and not feel yourself getting burnt. And that's what it feels like at this point – the skin is badly burnt and blistered, and the insides are burnt too, and raw. Which can feel anywhere from neutral to itchy to achy to burning (as if sprayed with pepper spray) to razor blades...

Home at Last

Karunadevi brought me to my last radiation appointment (with a Mardi Gras theme) on the way home from the retreat. We also talked to the nurse and a doctor who was filling in for Dr O, then to the other health center for a urine test, which came out positive for a UTI, probably because of preventative stuff I didn't do on the retreat. Then we had an excellent lunch at Fresh Choice. At 4 Robin brought me to Misha's where I told her my woes. Went into a very deep sleep on the table and felt wonderful when I woke up with no pain.

February 23: **Notes from the last chemo**

Julie and I went to chemo today at 8am. I've had a private room every time I've been there, which has been awesome. My oncology nurse C said I lucked out that there weren't new patients during the times I was scheduled. C has been both super-competent and entertaining. Found out he is fond of toffee, really should have brought him a prezzy, thought that yesterday with the radiation folks as well...

The formerly elusive Dr S dropped by. He was meant to be my main doctor but disappeared for a month right after I met with him for the first time. There was mystery around what happened – he did not tell anyone – well not C anyway, or the radiation oncologist Dr O. He seemed to have lost some weight and he seemed a little sad. I noticed a very slight interesting accent which I did not detect when I met him before. I'd like to know his story... but I suppose will not ask. He is my main doc moving forward. Once I get my HDR (High-dose rate brachytherapy) next week, I will make an appointment for a CT scan and one with him the day after to talk about it.

This brings up the whole area that I have thus far successfully avoided: speculation about what is going to happen. It is clear that for all kinds of reasons my life will (continue to) be drastically different from how it was a few months ago. And even though I've been incredibly low energy, I am antsy to do (non-cancer related) things. Will I live in San Francisco? Will more treatment be proposed and if so, will I do it? When I stop working for the Buddhist Center (I was laid off – given six months' notice – shortly before I got my diagnosis) will I get a regular job? Will I move in with someone in my family?? Will the tumor be

completely gone? What about the other ‘local metastases’? I do know that even if the tumor is gone and the eventual PET scan shows all clear, it doesn’t mean I’m done with it.

Anyway, Julie and I had lunch at Udipi Palace and I splashed out with a mango lassi which I drank in about one minute. Balanced by really good unspicy creamy tomato soup. Liquid – yes. Blenders are my friend. Rochelle brought by more excellent snackage with a “Weekly Treat” chart for me to fill out with things I like! She said my illness has brought out the Jewish mother in her which she didn’t know she had. Lucky for me! Pasadini made some nice simple borscht-like soup and we watched a crap documentary, “2012: an awakening”, which we both enjoyed.

I took my first Cipro this afternoon for my urinary tract infection. Since I saw Misha the pain is not as bad and there is no blood. I’m learning all the things that help with the different kinds of pain. Also need to have the energy to do it, and remember all the stuff to do, and when to make sure I have the stuff with me. I haven’t taken much of the vicodin at all, I haven’t mostly felt I’ve really needed it. I’m kind of a minimalist when it comes to taking medication. Definitely as needed, not so into the ‘just in case’. My inner thigh skin is dark red and blistered. I’m tempted to post a photo, but apparently my cancer blog self-disclosure has its limits. Certainly in some places I look like I’m about 5,000 years old. Or let’s not exaggerate and say 500 years max.

(I have to confess to having spent 30 of the minutes of writing this while sitting in warmish bath water. Super careful about electrocution. As has been pointed out to me more than once, dying in a stupid way at this point or possibly any point would be... unfortunate.)

True confessions: how I feel about other people complaining

There's a great comic about this in the book *Cancer Has Made Me a Shallower Person* by Miriam Engelberg. It's reasonable to think that I would be judgmental about your complaints... I have occasionally been impatient with repetitive whinging but I think that has been more the exception. These days, every time I hear a problem someone has, it sounds really bad. I think if anything I have more empathy. Sure, the complaints come from people who don't have cancer, but there are other ills. Recent examples: serious concerns about money; bad health; all the pain around comparing oneself to others and feeling threatened and insecure; worry about one's kids; mental illness; relationship ending... I see how critical of ourselves and anxious many of us are. How many things do you do that you feel at least vaguely guilty about? How many things are you worried about? Remember, even with cancer I'm still [Auntie Suvanna!](#)

I have become a lot less critical of myself since my diagnosis. This is at least partly from having somehow become psychologically a lot simpler... but I notice how I can just do what I need to do (say nine out of ten times!) and not feel conflicted or guilty. Now I want to lie down. Now I'm watching a movie in the middle of the day. Now I'm canceling something. Now I'm on retreat doing virtually nothing on the program!

Now I'm eating something that may not be great for me, but I'm not going to sweat it... Possibly I don't have as much energy for criticism (and other more psychologically complex functions). Once I have more energy I may pick it back up again, as if retrieving what's familiar from a luggage carousel.

This is a bit off-topic but I do think I need to express my needs more clearly. There are things about my experience that other people are not going to get unless I spell it out. For example, that I can't really be in the sun. That certain foods can (later) cause me pain. In a way I am very healthy, but tire very quickly, and am rather physically fragile. People know this in general of course. I probably need to know it a bit more. I am not used to communicating needs so much, or having so many to pay attention to. Anyway, tell me your troubles if you would like to talk about them. Most of the time I deeply prefer them to mine.

February 26: **Complaints about going out**

My massage was wonderful yesterday, but made me realize the degree to which leaving my house for more than, say, half an hour, causes some anxiety. My bladder is messed up so I have to pee often. I do not have a normal degree of bladder or bowel control. Plus pain, special gear I need to keep with me, and getting car sick... My friend commented that it's like having a baby! Anyway it was good to spend some time with Tong. I also managed to get in my Costco fix, which I need around every two years.

February 28: **Last brachy**

Laura and I drove down to Julie's in San Carlos last night, working our way toward my last cancer treatment which was this morning at 7:30am. Didn't get the fun drugs this time. No complaints, no pain. The nurse took some pictures during the procedure but they're mostly too depressing (for me) to post here. We did get to hear about a Bollywood birthday party Dr L had with his daughters where dancing was required. The nurse said it was the funnest party she had ever been to.

We went for falafels at this place Julie knows in San Jose from college, and I felt very shaky... then nausea, went ghostly pale. Not sure if that was because the meds were different. Anyway, back at Julie's, went into a deep sleep for hours. Feel fine now though still a little shaky. It's hard to get excited about it since I am getting more tired and nauseated, and have an infection. Still...

*

Opening the Door

from an article, 'Tearing open the dark', August 2008

Real spiritual progress involves pain. Our limits must be acknowledged, and pushed. People from every era and culture are deluded by common, spurious dreamings of heaven. We imagine that Buddhism, or something else, will bring us to a place where difficulties are eliminated, without our own effort. But this is not possible. Since we can no longer believe in heaven, we choose substitutes, and assign to them the attributes of heaven – where everything is easy and blissful.

The difference between the pain of spiritual practice and the pain we're accustomed to is that we can learn to appreciate the former – at least in hindsight. Because the pain that occurs as a result of a truly spiritual motivation, the pain regarded with some degree of spiritual insight and warmth, is a door to successive stages of total liberation. We may bang our heads against the door, and it may hurt, but if the door is opening, however slowly – what more can we ask? This process constitutes the most satisfying feeling I have ever known. It is the reason in Tibetan Buddhism that enemies and difficulties can be referred to as the 'Tantric Guru'.

March 20: A picture I took at acupuncture.



March 2012: The human body at peace with itself

March 4: **How am I? (Update from my perch)**

How am I? Pretty good. My hands shake. Generally I feel shaky a lot of the time, kind of like you feel when you haven't eaten for a long time, except the hunger part. I bruise easily, tire very quickly, and when nature calls, I have a few minutes to make it to a bathroom... I did walk up toward Twin Peaks yesterday with Dawn, made it to the overpass which is about a mile I think (it's a very steep walk). That felt good. Then we watched the [Louis C.K. show](#) he is selling for \$5 on his website. He's a comedian if you haven't heard of him. His nickname should be The Disgusting Philosopher. Some degree of anxiety about my future creeping in. So many unknowns. Trying to see it as an opportunity!

March 6: **Some useful toiletries and a meeting with a doctor**

I was feeling really depressed last night thinking about my employment/career/etc situation. Then I opened a package that arrived from Nora in Hawaii, which among many other lovely things included a bizarre bar of soap. Pasadini, Padmatara and I were laughing for a long time. It definitely cheered me up.

Dr O and the nurse said I am 'healing normally'. I told them all my symptoms and they suggested things to do, eg, more astringent for my peeling skin. The bathroom urgency (if you must know, both

kinds!) and fatigue will probably continue for a couple of weeks. This is the biggest difficulty as it means I often don't want to leave the house.

I asked for some specific info about what the scans mean (the CT scan in a couple of weeks, and the PET scan at the end of May). I had it pretty much totally wrong. The CT scan can't check the size or existence of the primary tumor. It's basically looking for something new in the lymph nodes or bone structures. In short, I'm probably not really going to know much of anything about my cancer status for three months. He said that if the CT scan did find something Dr S would probably suggest chemotherapy within a few weeks, a prospect that fills me with angst.

After the appointment I went for a short walk at the Sawyer Camp Trail, which borders what I think is the reservoir with the water from Hetch Hetchy dam in the Sierras. I need to start walking more again = more energy/less depression. It was a warm, pretty day.

Healing marathon

I seem to have switched from downing coconut water to eating oranges – at least three a day. Trying to keep up with the acidophilus twice a day and other maintenance things I'm supposed to do, all of which has gone lately by the wayside, probably to do with feeling depressed, unmotivated and anxious. Lots of emails to catch up on, and I lost my phone (going to give it a few days.) Going to pick up the moisturizing again, the acidophilus, supplements, and walking and meditation... so much maintenance.

Apparently I have a “vesicovaginal fistula”. A fistula is an “abnormal tubelike passage within body tissue, usually between two internal organs” – such as the bladder and vagina. I don’t care about this so much at the moment since I don’t have any symptoms from it.

I’m eating meat once or twice a week. This is because I crave protein (and have been told to eat a lot of it), and it’s too much effort to get a lot of, and varied, protein through vegetarian sources. Also I am eating what I crave, which sometimes is oranges and sometimes is wonton soup.

I had three helpful health-related appointments yesterday. First I saw Alan the shaman. Seeing him was really great. Mostly what he did was help me relax... for me it was very, very simple. I just felt all the various areas of tension in my body, then I felt it be relieved, and I felt that something was clearer, lighter. At some point (for Alan) a cheetah appeared, which is excellent. Then I saw Misha the acupuncturist, and went to the chi gung class next door. The net effect of it all was that I feel both more relaxed and more motivated.

March 7: **The human body**

At Alan’s I ended up spontaneously reciting part of a poem by **Tsong Khapa**, a Tibetan Buddhist master from around 800 years ago. Alan suggested I recite it every day. It has been a favorite for a long time. It is what I must remember.

The human body at peace with itself
Is more precious than the rarest gem.
Cherish your body.
It is yours this time only.
The human form is won with difficulty.
It is easy to lose.
All worldly things are brief,
Like a flash of lightning in the sky.
This life you must know as the tiny splash of a raindrop
That disappears even as it comes into being.
Therefore set your goal.
Make use of every day and night to achieve it.

March 9: **Support group – not**

I went to a support group yesterday in South San Francisco. Bad news is, no one but me showed up. I told the social worker that I wasn't even sure what I wanted to talk about, just that I didn't know anyone else with cancer... Good news is we ended up talking for an hour and a half. It was great. While she doesn't have cancer (as far as I know) she talks to a lot of people who do, and their oncologists.

One of the things I told her was that I wasn't particularly afraid of dying; my fear is more around quality of life and a potentially constant struggle with cancer. She said that 'spiritual' people, by which she meant people who pray or meditate, all spoke in a similar way about

death. She said some other people can't even say the word. All of which I found surprising, but no doubt I am fairly out of touch with the average Joe as it were.

She also said that sometimes oncologists don't tell their patients bad news, or they say they don't know. (But if she asks the oncologist about a patient, they will tell her.) Usually medical oncologists (eg Dr S) are better at it because they do it more and have more of the big picture than, for example, a radiation oncologist. She said it helps to ask very specific questions, and if you get a bunch of different answers, to take something in the middle. All of my doctors have said they don't know... it seems like they don't.

Examples of good questions

Do you foresee I'm always going to be on chemotherapy?

If I don't do more treatment, how long would I live?

Re. more chemotherapy – What is it buying me? What if I don't do it?

What would a decline with my type of cancer look like?

Vacations

Take a vacation 'between treatments'

Refundable tickets

Not too remote (close to a hospital)

General advice

Don't think about making huge changes, eg. a stressful full-time job

Think about doing things I enjoy, friends, laughing, vacation

Think in terms of... simple... de-stressed... money... stability

March 14: **Gratitude and underpants**

I think that I have never naturally said the word 'underpants' in a sentence. I mean, it just doesn't sound right. Even worse: panties. I guess I was raised on 'underwear'. In England, they say 'pants' and 'knickers' to mean underwear, which I think is a better system. Which somehow brings me to my point... I am wearing women's underwear today. I have been wearing big ugly men's underwear for a few months now, which probably would have been much more painful for someone who's more of a lady than I am. Still, I was pretty sick of it.

I meditated today for the length of time it takes to burn a long stick of Shoyeido White Cloud incense, my favorite, with one rain-spattered window open. Rainy warmish San Francisco air is nice. I slept 'til 11am and felt great when I woke up. Grateful I can sleep as much as I want.

March 16: **No one knows when they are going to die**

I ate a spicy burrito by accident (I mean I forgot to say no hot salsa) and had no ill effects, or nothing worse than usual. Which is cool, because I like spicy food. In general I am not eating super healthy food anymore. As evidenced by the half-pint of Ben and Jerry's last night. I'm doing all right though. It occurred to me that maybe I've been more tired lately because I am eating less protein. I used to have a shake in the morning which had 20 or 25 grams of protein. Going to start doing that again.

If you mention to a Buddhist that you don't know how long you are going to live, they may tell you that none of us knows. When I noticed I was getting irritated more often lately, this was one of the examples. In addition to feeling like a lack of kindness, it might be to do with confusion about the difference between the relative and ultimate plane. Ultimately, yes, we are all in the same boat. Relative speaking, some of us are already spending a lot of our time bailing water. I led a meditation at sangha night, which I really really enjoyed, had a strong sense of coming home. I felt so happy to see people. I got all misty saluting the shrine.

I went to a support group today at Geary Street. I didn't say much; listening was rather fascinating. Some of those people have dealt with the uncertainty of cancer year after year and endured a lot more pain than I have. I felt a lot of compassion for them. One woman had had cancer five times, three different kinds of cancer! Another woman (closer to my age) had bone marrow cancer and was hospitalized for chemotherapy – seven different chemo drugs administered 24 hours a day. A guy said he was in so much pain for around a month he wanted to tear off his face. One woman who had gotten her diagnosis in February said she sometimes cried all day. One lady had had a tracheotomy.

There was some of what I would call lecturey advice giving. The social worker was good. At one point she said to one of them, "Let's let Bob tell us about his experience." People talked about the importance of letting the emotions be what they are, just crying or being unhappy

when that's how it is. These people have really fought hard for their lives, possibly much harder than I am capable of, or maybe that's just not my language. Mostly I did not feel I had a lot in common with them. Almost all of them were from a different generation, many years older than I. I realized that none of them have any certainty about their situation, and that no oncologist is ever going to say to me, Here's what's going to happen. The treatment tends to entail a lot of suffering over periods of time, and no one knows if it's going to work. That's just the way it is.

March 17: **Down the rabbit hole**

I was meant to be leading part of a practice day this morning, so I set my alarm, which is one of those that emits light rather than sound, for 9am, and put it on my magazine rack angled for maximum light in my face, so there was no chance of me missing the wake up call. But when I woke up this morning, the clock said 12:15! Crap! I missed the part I was meant to be leading! How did it happen? I guess I slept through it or it didn't go off. Crap! I went into the kitchen and Pasadini asked, Weren't you doing the practice day today? I said yes, but I failed to wake up, I don't know what happened, but I missed it. I was still very tired somehow so I got back in bed. When I woke up again it was 12:20... hmm. Only 5 minutes had passed? My watch was on the nightstand – it said 10am. Or was it upside down? Have I fallen down the rabbit hole? I felt intensely disoriented. Turns out that my clock doesn't really run when it's not upright, and since Pasadini wasn't even home, that conversation must have been a dream, and I

probably woke up the first time at around the right time, but didn't know it. Now it was 10am, the time the practice day was starting, and there I was, confused, with mascara smeared under my eyes and a severe case of bed head.

I was down there by 10:30... Then I didn't grasp what time lunch was, even though Padmatara kindly wrote out a schedule for me. Being so continually confused about time kind of upset me. Perhaps I am jumping back in a bit too soon? Anyway, it was great to see people.

March 18: **The left ischium, etc.**

This is my 75th post on this blog. Who knew that all it would take was cancer to make me prolific...

I got a 120-page PDF file recently containing some of my medical records from my health plan. It doesn't include a lot of things, such as email correspondence. It's mostly about the scans. Anyway, apparently I have a "mildly generous uterus", so that's something.

March 20: **Hello, depression**

It's time for me to plan to do something different than growing frustrated in San Francisco waiting to find out my projected life expectancy... You think?

March 21: **Depression P.S.**

I don't want to overstate my depression. I felt that in the interest of balance I should mention it. Apparently depression very commonly happens post-treatment. I am working with it, it comes and goes.

Looking over past blogs I realize there is real progress – for example, no more terrible clam. I have a fear of having to do chemotherapy... but come to think of it, my hair falling out and being nauseated sounds way better than being burned by radiation.

March 22: **Thai massage rocks**

I had a great day. Paulette and I went to a new place up the street that offers traditional Thai massage. They give you a sheet to write the pressure you want (Gentle, Medium or Strong) and circle the parts of the body you want them to focus on. There was also a section with checkboxes next to conditions, such as asthma, arthritis, and... cancer.

I did the right thing in that I did not check that box, since there isn't anything they can do or not do about it. All it would do is potentially mess up the massage! I circled both Medium and Strong. And this woman called Kai kicked my ass! She also asked several times whether it was all right, which is partly why it was. When she stood on my shoulders, crushing apart my shoulder blades and my lungs, it was hard to answer, Good.

March 26: **Greens and family and what's next?**

I think because my hair is now short, people have commented a lot on how much Paulette and I look alike. One woman suggested we must be mother and daughter and both of us gave her the stink eye so she said, I meant sisters!

Big day yesterday. Brunch at Green's with Julie and Morgan and sisters and niece. Hotels and airport arrivals and departures.

March 27: **Brazilian Jesus**

I've been having memorable dreams. One was that I was writing a super-important poem. All this stuff was happening but the most important thing was to finish my poem. I only remember the first line, something like "Looking for Brazilian Jesus".

In another one I suspected that I was dreaming. So I asked myself, How can I tell if it's a dream? There is some question I need to ask but I can't remember it. When I woke up I realized the give-away is asking that question. (If you are asking, it's a dream.) I've also had two dreams about my ex-husband Michael, who I haven't thought about in years. (We were married in 1983 I believe and only stayed together a few years.) In the dreams, I felt a great deal of tenderness and longing.

March 28: **Labyrinth**

I have been reciting the Tsong Khapa poem in morning meditation. The reason, or part of the reason, I can let go of anxiety is that I am committed to enjoying my life. Kathy commented today how calm and happy I seem. She said I didn't seem angry or depressed or sad. I said, I am a bit sad, but that's all right.

A theme that is coming through lately is that to some degree I am expecting to die in the not too distant future. Of course, I'm also aware that this may not happen. Sometimes I am more afraid of life than of death. I don't know how to explain that. I'm not depressed.

Life has many joys of course, but it is also relentless and confusing. Having had this cancer experience, with my tenure at the Center ending and my travel options severely curtailed by my medical situation, I don't know which direction to move in my life.

But all this is just stuff going on in my head. If the doctors told me I was very likely to be fine and cancer-free forever, that would cause certain kinds of thoughts. If doctors told me I am likely to die in a year, that would cause other kinds of thoughts. So far, doctors have no predictions, and whatever happens is what happens. Sometimes that means potential scenarios unconsciously and subtly develop themselves. It's difficult to see perspectives or mental states as temporary. Because there is some kind of thread that is linking them to the past, the future, to everything, they can seem substantial. Tomorrow I will perhaps know more about my prospects. P.S. I love the word labyrinth.

March 31: **My senior citizen pelvis**

On Wednesday I had a CT scan; a meeting with Dr S to discuss it; and a complete bone scan. Doctors are so geeky. They talk so fast, barrage you with technical information. At least, all my oncologists do... But by the time Kathy and I had asked many questions, what we ended up with was a best case scenario on my CT scan, which is that they didn't find anything new. The pelvic bone sclerosis (scarring) is unchanged since November. In other words, I have responded very well to the treatment.

There has only been one study of vaginal cancer, and it was only 20 people (not statistically valid I think). In that study, there was a 50% chance of people with advanced stage cancer living more than five years. Women with advanced breast cancer have even worse odds, based on better statistics, only one third live more than five years. On second thought I think it's probably better not to have these numbers! As Dr A says, these kinds of statistics are not relevant to individuals. In any case, as I'm sure I have said before, there is no survival data for vaginal adenocarcinoma. Six months from now I should know if this is an aggressive cancer; the PET scan will also be a major milestone.

Is local metastases better than distant? Yes, but likelihood of it turning into distant mets is very high. Is cancer in the bone more life-threatening? No, best to look at it all as one cancer. Is the best way to evaluate my primary tumor with a physical exam? Yes. I will make an appointment with Dr K. He also suggested I discuss my concerns about planning my life and so on, with a social worker.

I felt good after this meeting. It seemed like it was the first time I had gotten any info about my response to treatment, and about the future. Before then it had all been "I don't know. Let's see what happens." If the PET scan in May/June is clear, I'm good to go. I will get a CT scan every three months for say a year, then every six months. If the scan is not clear, Lands End every three weeks for 18 weeks.

Bone scan

A visit to Nuclear Medicine department, an injection of a radioactive tracer, a trip to Walgreen's and a wifi cafe so Kathy could write her blog post. Then back to the hospital to lie down very still and watch a sort of square white plate with a crosshair in the middle of it move very slowly from my face to my feet. Having to lie still on a scanning table is, generally speaking, rather relaxing.

When I got home there was an email from Dr S: "The bone scan shows the following (essentially involvement of the pelvic bones but no other evidence of widespread disease involvement) [in other words, metastases remains localized to pelvis]. I would recommend pamidronate infusion every 3 to 6 weeks as we discussed." I emailed him back with a few questions. His reply: "The changes in the hips are related to arthritis according to the bone scan. The other findings are related to the cancer and are in line with the prior PET scan. Please let me know if you would like to proceed with the pamidronate infusions." Cancer and arthritis. Grand. My pelvis is quite the senior citizen.

Well, I had 24 hours of thinking I would likely be free of scary drug regimens for at least several months, but alas... I have a lot of questions about this. I am thinking that unless it is really crucial, I don't want to do it. But we'll see. I need more info.

The creative mind

from a talk on creativity, 3 February 2010

The creative mind is characterized by ceaseless productivity. This is interesting. I think some of us have a sense that we are only worthy human beings if we are productive. But this is a different thing. This is productivity that has absolutely nothing to prove. If we feel we always need to prove ourselves, where is the kindness in that?

For myself, I think it's good to waste some time. If this sounds really hard, probably all the better as something to try. Sangharakshita says, "You don't have to justify your existence by being useful. You yourself are the justification for your existence." What compels the creative mind is not justifying existence, or proving or avoiding anything, but simple and pure and free spontaneous energy.

The creative mind does not necessarily find expression in 'works of art'. You might think, Well what is it doing then? It can manifest itself in all kinds of areas of our lives. But a general point I want to make is that creativity is playing. It's bringing a playful attitude to life. We don't need to be martyrs. Bodhisattvas joyfully play at everything they do.

Sangharakshita says, "One can regard this as a spontaneous overflowing of [their] inner realization, which transcends the immediate situation."

The creative mind is above all an aware mind. And being aware, or rather, being Awareness itself, the creative mind is also intensely and radiantly alive.



April 1: Tarkarunya's painting of the Medicine Buddha. Notice San Francisco in the background!

April 2012: The power of ideas

April 1: **Medicine Buddha**

A tube arrived in the mail from “TKY” in West London, which is Tarakarunya, who I was ordained with in Tuscany in 2001. I think she must have painted it! There was no note with it. It is very beautiful. Kathy is getting it framed by the super nice guy on Valencia, so I will get it back around April 12. Can't wait!

April 3: **Cancer helps me do nothing**

It seems that when I don't have to get out of bed, I don't. I fully plan to, and know that it is the right thing, but I don't. My bed is like an anti-siren that keeps me from traveling... I have lots of things to do, just nothing that has to be done right now. You wouldn't think that someone lying in bed all morning would have issues with it. But this morning I noticed around the edges thoughts like, Oh, does this mean I'm depressed? How can I live without caffeine? And I thought about the things I ought to do. Meditate, figure out solitary retreat, walk or find a yoga class, make this appointment or that one, figure this or that thing out. Fact is, I always feel like I should be doing something, unless it's Sunday morning.

And as long as I am reveling in self-disclosure, I may as well add that there is also a tinge of fear, that the henchmen of the protestant work ethic will swoop down and serve me a cup of good coffee. If I'm not going to get up, why not just lie in bed, unified? I decided not to worry.

I lay in bed until noon, thinking about stuff... For example, that around four days ago, taking a shit stopped involving pain.

I may stay up at the SFBC land for the last two weeks of April. In spite of pondering Mexico and Hawaii, I may end up in an eco hut on the northern coast of Oregon after that. I don't know if I have the wherewithal to set up anything more elaborate. Plus, I have a car. I am not in a hurry. I have no ambition. I have no bucket list. I move slower than I used to. I thought about how strange it is to have people worry about you and not want to bother you. It's strange influencing distant friends and acquaintances by virtue of one's disease. The me and the you of me having cancer is not to be sniffed at. There's a lot more to this, but alas, I am somehow ready to get out of bed. I leave you with a few words from Yoda: "Try not. Or do not. There is no try."

April 4: **Busy (for me) day**

I'm sorry if reading my last post made you wish you could sleep in, or made you think I am lazier than you already thought I was. It's true that I have a great love of sleep, cancer or no cancer. (Apparently a sleepers' gene has been identified. Around 50% of my family has it, unless they're at my house, in which case all of them have it.)

Today I did four things. Went for another consult with Misha and Elisa, met with a social worker for half an hour, chatted with Tong for a while at the "Sugar Bowl", went to the weekly support group at UCSF, and meditated at sangha night. Pooped!

The support group was great. Such nice people. The consult with Misha was also great. She did emphasize anti-inflammatory foods, especially no or very little sugar. Stevia is OK. Ack. For a couple of months I didn't eat anything with added sugar in it, and was mostly not tempted by such things. This may be difficult at this point, but I'll try.

April 5: ¡Ay Caramba!

Today I had a somewhat painful exam (because of scar tissue) in Santa Clara with Dr L, the doctor who did all the internal radiotherapy. The first thing he said was: "Beautiful, good." Because my tumor is gone. He said that it was a large tumor, and he has no doubt that it has completely vanished. I don't know exactly what this means in terms of the future but it would seem to be another, more significant best case scenario. When I first met him in January he told me that he was sure he could get rid of the tumor, which was far and away the boldest statement any doctor had made at that time, or since. I thought, "We'll see." (Hope and fear must be managed!)

He said doctors have different styles; some rely totally on scans etc., but he relies on how it feels. He said I could get the PET scan, wouldn't hurt, but no more information would be revealed from it, and it would not affect future treatment plans. Bless his cotton socks! He has felt and treated thousands of tumors. He said this week he had treated cancer in eye, prostate, and ovaries...

He had been concerned that the tumor was so deep that once it was gone I might need surgery to patch things back together. Surgery might still be necessary in the future. For the next year or so, scarring from radiation is a risk. (I have no idea why scarring continues for so long after treatment.) For example, my urethra could become blocked by scar tissue and would need to be surgically stretched open again. Also, the vag could shut down as it were, so that sex would not be possible, or just painful. There are things I can do to help reduce this possibility, but nothing much to be done about the urethra as far as I know.

Padmatara and I couldn't quite get our minds around this news. We went for veggie burgers and pinot grigio at the Beach Chalet. The water was super choppy, incredibly cold wind out there today. We watched para sailers zooming by.

April 7: **In or out of the world of cancer?**

I'm a little concerned that I am still so tired. How long will it last? Or am I no more tired than the next guy, just that I can sleep as much as I want to? How much energy am I supposed to have? I seem to have less than other people. I think the docs did tell me that the fatigue could last for a few months. In the afternoon I went for a walk up to Bernal Hill with Karunadakini, then met some folks at the Lone Palm, a bar up the street, for celebratory libations. I had a ginger beer. Walking home I wanted to stop and buy ice cream but somehow refrained.

A few months ago I left my world and entered the world of cancer. Now maybe I'm coming out of that world. I don't know whether I am or not. I'm assuming I still have secondary cancer/bone sclerosis, but I don't know what the implications of this are. But in some ways I don't want to leave cancer world. I want to keep having a lot of space in my life, and for things to be simple and loving, and to be able to rest when I am tired, and to spend hours lying in bed absorbed in my thoughts, writing.

You might say, wow, do you want cancer or not? What I want is a sane, spacious, and reflective life. I dread my awareness thinning out because it has to take in so many things, and then starts hungering for them... Of course, I don't want the pain. In the support group yesterday someone suggested a website that seems to be just people with cancer discussing their issues. I am learning a lot. I saw there that even though few people have vaginal adenocarcinoma, many, many people get pelvic radiation. Anyone with cervical cancer gets a virtually identical treatment to what I got. I saw that some of the people who beat cancer end up disabled from the treatment, either because they lost or wrecked a body part, and/or because they are in constant pain.

April 8: **A visit, a tower of song and a serial killer**

Delightful Savanna is here for the weekend from New York. After a nice breakfast at Chloe's and ambling around Valencia Street, we went to the [Conspiracy of Beards](#) concert at the Center. It felt like church singing in the most genuinely uplifting sense. Or anyway, my kind of

church. The power and beauty of the voices brought out wonderful details in the poetry of Leonard Cohen.

I crawled into bed and watched the documentary 'Aileen: Life and Death of a Serial Killer'. It was haunting and profoundly sad. I have had very little physical violence in my life, but somehow I very deeply resonate with the pain of situations of extreme violence, especially against women, and the sad stories of the perpetrators, both of which are part of her story. I remember reading an account of a Cathar (early Christian sect) woman being burned alive. I cried for a long time. I feel silly that I wrote about wanting to stay in bed writing all day. I hope that you realize that what I write here is true, but only insofar as the present moment lasts.

April 9: **Info**

Just had a chat with Dr S. He said there was some concern about my lungs from what showed up on the CT scan (also could be nothing). So they still want to do the PET scan in May. If there is disease progression, there will likely be 18 weeks of chemo. If there is nothing, no chemo, and things will just need monitoring.

April 10: **I didn't think anyone liked me so much**

Were people not sweet before? Or was I not sweet? Or was I oblivious to affection? It seemed before like no one, or most of no one, gave a crap. Now people want to talk to me before I kick the bucket presumably. Don't get me wrong, I like it. I should keep this cancer story going for a loooooong time.

I realized something about Dr S. I had asked him to be direct. Based on a couple of our conversations, I'm not really sure that he can be. I mean, he can be direct about conveying results from studies, but those things aren't what I meant by being direct.

Anyway. The way individuals have responded to my illness seems to correlate to their past experience of illness. In other words, if they nursed an ill husband, or had a close friend with breast cancer, etc., or dealt with some kind of illness themselves, then they're sort of 'here' in a way that other people are not (even if they're not geographically here!) In other words, if you have had little experience of illness, pain or disability, you don't particularly resonate with someone who is very ill. This is not a complaint at all. (It's exactly how I was around five months ago!)

April 12: **Food issues**

I went to the UCSF support group yesterday. I like going to that group, in spite of being really sensitive, and getting rattled by people giving unsolicited advice, which the world seems to be full of, even when it's not directed at me. Energy-wise I am very high-and-low still, also sometimes unable to sleep.

Misha has told me that studies show more and more of a link between sugar and cancer growth, so I thought I would go back to my zero sugar policy, but haven't. This is simply because of the amount of discipline and effort it takes. For example, the jam I have has sugar.

When I went to the bar, it was either water or a drink with sugar in it... I am certainly eating a lot less sugar than I would like to.

I'm also eating a lot less meat (by which I mean, flesh of any kind), as the cravings are less frequent. I notice how much discipline and effort it takes to be a vegetarian, for example, when you're at an Italian restaurant and the vegetarian choices are all starchy with little protein. I suppose in the past I would have tried to avoid such restaurants, or maybe I didn't feel like protein was such an issue. Still, I'm around 95% vegetarian at this point. I guess I am still to some degree prioritizing my health over the lives of the animals. And I'm craving caffeine! I suppose I am wanting to go back to my previous routine. I'm bringing no sugar on my solitary retreat... Feeling better brings new challenges...

April 16: **Broken, or, the power of ideas**

I am on the first day of my solitary retreat at the SFBC land in Lake County. Most of this I wrote in my tent last night: The Power of Ideas sounds like a corporate marketing slogan. But the thing is, ideas are powerful. And slogans are often true. By an idea, I mean a thought. A thought like one I had today, my body is broken. By which I understood myself to mean hurt. Very deeply hurt from the machine- and chemical-generated abuse it underwent. Part of thinking is re-thinking, discovering what you were thinking before, that you didn't even know you were thinking. I thought of my treatment as temporary, with temporary effects. Dr O told me the side effects would go away

after a month or so. But here it is, two months down the line, and side effects abound.

For example, I had a hot flash tonight. I have never had a hot flash before. The occasional stabbing pain deep in my gut. Soreness in my hips and knees. Arthritis... was it caused by the radiation? I don't remember hearing about that as a possibility. Painful urination. More gassy, less bowel control. Some of my teeth are sore. I sleep 10 to 12 hours per night. An occasionally intense need to be alone, inarticulate, can't quite explain, a deer in the headlights. Confusion. A dream about driving, trying to get home, and everything moving around, home is getting further away and the route more confusing. Finding being around more than one other person, even people I know and trust and love, stressful. Strange effects from food. Like sometimes after I eat certain foods, normal foods that people eat, like breakfast cereal with wheat in it – but it's not normal because it doesn't have any sugar – my vagina itches for a while, which makes me anxious. First the itching and before you know it you have cancer again. (This is also a thought.) Or sometimes my face will itch.

One morning, say, I feel better, energetic, and I think I am done with recovery. But the change seems to be non-linear. The next day I feel broken, weary. I thought that on around March 22, all the pain and trouble would be over, or close to being over. And that thought keeps getting friction. It seems that in some ways my body is irreparably damaged... or is that just an idea? In any case, my body feels different – behaves differently – than it did a couple of months ago. They aren't

differences anyone would wish for. Grief coming from my body today, crying and crying. It's a relief to let some of it out. Meditation feels emotionally healing.

I just googled "radiation side effects arthritis" and found more online forums from cancer survivors. Here is a quote from a man who had anal cancer and got 26 radiation treatments: "The collateral damage has been enormous. It's been over five years now since I had this done and it is only getting harder to move around as the years pass... I was only 43 when this happened – the radiation "aged" my body exponentially." Geez, why didn't anyone tell me how badly my body was going to be messed up? I have to start doing yoga!

Vagina. Vagina. Vagina. It used to be a sexual word. It used to be a private word. Now it's like Leonard Cohen's broken hallelujah.

April 30: **Trying to drink whiskey from a bottle of wine**

This is a line from an old Elton John song (or are all Elton John songs old?) that went through my head many times during the two weeks I spent alone at the SFBC Sugar Shack in Northern California. I wrote a few draft blog posts, none of which survived, because I felt they were too whiney, they were trying to drink from the wrong kind of bottle.

My tumor, the primary and biggest cancer, is gone. I was told by the doctors and expected, and I suspect others expected, that my body would roughly go back to how it was before. Yet I seem to be suffering, in one way or another, more than I was during treatment. I spent the two weeks, among other things, getting to know my body

as it is now, and not wanting to get to know my body as it is now. I had many dreams of frustration, trying to pack, trying to ascend a staircase, trying to take a shower... many efforts thwarted. I also heard doorbells, and someone knocking at the door, while in the house, and smelled incense (in my car) when there was no one there!

The health section of the New York Times recommends that people with arthritis avoid staying in one position for too long. Which is a big part of what meditation is, of course... at least the kind I have mostly been doing for 20 years. Dealing with this change is going to take a lot of getting used to and a lot of creativity. Of them all it is what makes me the saddest. I do feel that in four months, my body has aged ten years. I've been doing yoga every day on retreat, and this helped my pelvic bones feel much better. I will do what I can to counteract the effects of the treatment, and who knows how things will be in a year, but for the moment it is, off and on, deeply depressing.

On another note, I just sent my email re-entering the consultation process to become a preceptor and ordain Dawn next year, the prospect of which makes me very happy.

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Buddhism vs. the Visceral Responses

27 August 2008

The minute you read about mindfulness, or some other super-practical aspect of Buddhist practice, you know in your gut that it just makes sense. It may even seem that it explains your life. Buddhism is just sensible and accessible, especially modern expositions on it. You don't have to "suspend disbelief" or perform mental contortions to be able to relate to it. It's as if someone had dug down into the dark recesses of human experience – including all the things we kind of know but don't fully want to know – and wrote it down, or spoke about it. It's like turning a light on.

But in actual experience, in the business we all have of being alive – or wanting to be – in each moment of every day, the teachings of Buddhism are relentlessly, even viscerally, counter-intuitive, so that in the course of years of practice we may discover many of the same things over and over again. We may learn something, we may think we're 'done' with it, but then we carry on with the task of incorporating it at successively deeper and deeper levels.

Spiritual practice is about the Herculean but somehow satisfying task of translating the realities of thought and word into deed. In attempting it we are confronting the ongoingly challenging task of expressing what we already know through our way of living in each moment. Our practice functions not to teach us new things 'from the outside', but simply to remind us what we want to be doing. It reminds us to apply

what we know to countless knee-jerk responses. It also somehow helps us do it.

The teachings, among other things, tell us to open up to the momentary and the abiding trials of everyday life, of every-moment life. But our gut doesn't want us to do this, or at least our gut often doesn't act enthused. We have to learn the thing over and over again. We have to have a thousand of the same Ah-ha moments. Maybe not a thousand. Maybe only ten. But I enjoy having them.

Song

10 February 2009

I marked the moments of being lost
and being lost was a longing
a song

left on my lips traces of rind
as one hears train sounds
but no train

I marked the moments of the song
by being lost
my compass

as if, before entering a lake
I took the clothes off my clothes
marked the moments on trees

I followed until I couldn't see
not even rabbits,

not even loss,

there was no trail,
only longing and a song

I marked the moments

being lost was my
song

May 13: A recent photograph by me of a 1970s drawing by me of a 1960s photograph of me with my cat in the dryer.



May 2012: A kind of trust

May 2: **Doodles for recovery**

I went to a three-hour art thing today for people with cancer. It's part of the larger [Art for Recovery program at UCSF](#). They got it going on over there. I went to a therapeutic yoga class yesterday. There's dance, pilates. It's all free and open to the (cancer patient) public.

It was nice to be around people who have/have had cancer. Most of them are either disabled by/in pain from the treatment they had years ago, or they are still actively battling the disease, sometimes over many years. They seemed like a pretty tight-knit group but they were also very friendly. I felt understood, and listening and talking while doodling is excellent.

May 4: **Compassion**

A couple of nights ago, making my way home from a solitary retreat, I stopped to visit my friend Lisa who – after many years of apartment living beneath a freeway in Oakland – now lives in a house in Novato, at the north end of Marin county.

She takes care of a 91-year-old bed-bound Irish woman called Betty. She has a delicate face and manner. The most striking thing though was how cheerful she was. She thinks about people who are suffering and prays for them in her spare time, and most of her time is spare, she can't really do much else. I got such a feeling of peace and kindness and lightness from her.

I guess if you have complete faith in a God who you feel is always doing the right thing, there is nothing to be pissed off about. Perhaps the Buddhist version would be complete trust in the basic principle that whatever happens is contingent on myriad conditions, which in a way is the opposite of a great being making all the decisions, but similar in that a kind of trust in the reality of all situations becomes possible. Perhaps both attitudes can produce a deep sense of a lack of control, a letting go that is incredibly freeing, and conducive to happiness.

Of course, meeting someone who has been unable to get out of bed for 10 years puts one's own suffering into perspective. You might say, well, she's 91 years old, it makes sense that she's very ill. A situation might appear to be more or less tragic depending on one's circumstances, but at the end of the day, suffering is suffering. Does one ever think that suffering is supposed to happen, that it's the right time? There's a degree of tragedy, at least for the person who's got it going on. I've been feeling sorry for myself to some degree, and meeting Betty put that into perspective.

She seemed genuinely happy and light-hearted, without denying what her difficulties were. She said, "I miss being able to do things." She had been a very busy woman in her life. She was grateful for the care she was getting, and aware of so many others who do not have it. And she was sad to have virtually no living friends her age, but accepted it all with a striking grace and engagement.

Betty made me want to think of other's suffering more often, to be kinder.

May 13: **The mask**

Through Love all pain will turn to medicine.

Rumi

This post is about conflict. The conflict I felt when my mom wanted to take back the stereo she had just given me, which I didn't want, but had accepted so that she would get rid of it. Irritation at nothing, at air, at air acting the way air acts. She assured me if she didn't use it she'd remember to give it to me later. I assured her she would not remember. Why? Why be so linear? Why start a sword fight with a windmill?

I left San Francisco motivated to be kind, to see behind the masks. George Orwell: "He wears a mask, and his face grows to fit it." People do stuff, they can't help themselves, they want something. We want something, we grasp, harden, soften, loosen, tighten, half the time not knowing why, what's underneath. There's confusion behind a lot of what we do. So I resolved to try for a time not to be so deeply distracted by appearances. To look beyond the mask and see that compassion is the only sensible response.

And then the internal conflict about applying for SSDI (social security) which I finally did yesterday. Do I really want to? Am I sick enough? Will they give it to me? What if they don't? Why didn't I apply earlier? Because I thought I would be, at this point, either very well, or very

sick. I didn't consider other scenarios, nor did they occur to me, even once. Yes or no. Yes or no.

And seeing how I use food for comfort... for something that is not technically what it is for. The conflict is some sense of, it shouldn't – I shouldn't – be this way.

And always, I should meditate more. Especially lately, feeling disconnected from my formal sitting practice. Shoulda coulda woulda.

Conflict is painful, and yet trying to get rid of conflict is to add another layer of pain. In a way, trying to be kind makes not being kind more painful. And that's OK too.

The kindness that I cultivate for others must also apply to my own failures, my own confusion, my own irritation, my own losing of my way.

I would like to write more, but I must leave now for a week's meditation retreat up in Marin county.

May 24: **Real things remind me of fake things...**

...like the clicky bugs at Spirit Rock that sound like a quickly shuffled deck of cards. The sound of cawing crows outside the shrine room evoked an image of Google's Angry Birds. Years ago, partly due to altitude sickness, a mountain in Nepal reminded me of Disneyland mountains. Before even that, I was accused of plagiarism by a famous poet at Cal, partly because I thought of Brutus primarily as a cartoon character. Anyway.

Something's always pointing to something else, especially words, they're always leading you somewhere. Cancer must be one of the most fear-inducing words in the English language. Say it: Cancer. Where does it take you? The word changes the body. Chemotherapy, another doozy. The radiation I got ended up being far more painful, with longer term side effects, but I don't think radiation is one of those words.

I want to say a little about my recent retreat at Spirit Rock. The main thing is that I was able to sit in meditation more than I thought I would, which was an absolute joy. I did a lot of yoga to stretch out my hips which are so tight. One day I even felt a great deal of peace in my body. But then the next day it all hurt (sitting and doing yoga, lying in bed at night with my sacrum throbbing). Last night, my friend Stephanie helped me refine some simple yoga poses and advised against others (like the lying down twist, which I used to love but which hurts now). (Stephanie has lived in Pune, India, near Iyengar's school, for many years. She travels all over the world training teachers of therapeutic yoga.) She would suggest something a tiny bit different from what I was doing, and my body would suddenly feel so amazingly right. After a couple of minutes, I felt so happy. In general I have been in very good spirits since the retreat, which is nice, since transitioning off retreat often seems to be very difficult for me.

The type of practice they do at [Spirit Rock](#) is very similar to what I am used to in the [Tiratna \("Three Jewels"\) Buddhist Community](#). Ours, it must be said, is more 'religious' in that we do rituals and get funny

names when we're ordained. We also, I think, emphasize kindness, community and creativity more, whereas (it seems to me) they're all about meditation/ mindfulness/ wisdom. I loved their Equal Opportunity shrine. In any case I am grateful to them. My last 'retreat allowance' from working for the center paid for most of the retreat; it dawned on me that I need to figure out a way to get on retreats, moving forward...

One other thing about the retreat. The first day or two I felt this sadness, but as if I were somehow out of touch with it. The next day I stopped taking prozac. (I've been taking a small amount (10 mg) of fluoxetine for about a year primarily as a perimenopausal mood stabilizer. But the treatment has abruptly removed the peri...) One is not supposed to just stop it, but I figured I am taking such a low dose it would be fine. And it was. I felt more in touch with myself. I also stopped taking the masses of supplements for one day, which helped my digestion. After that I cut down on a few things. My condition continues to improve, albeit very, very slowly.

Dr S is leaving town again. So frustrating. I'm sure he has a good reason, but he can't function well as my main/coordinating doctor if he's away so much. So no meeting after the PET scan, but he has a backup, Dr R (not even the same sub as last time he left!) who I will hopefully be able to talk to. (Alternative is to wait ten days to get the results.)

May 27: **Worry and sex (not as interesting as you might think)**

Another thought I had on the recent retreat was... Well, really it felt stronger than a thought, it felt more like a vow. I thought, I cannot live for the rest of my life, however long that may be, afraid of getting cancer again. I simply will not do that. At the same time, I do feel committed to taking better care of my body, eating more nutritious food, getting regular exercise more consistently.

Over the last few years I considered, and eventually lost interest in, the idea of becoming an anagarika (shorthand: a nun), at least in doing so formally, but now I'm coming at it from a different angle... My body does not tend to feel sexy. More often it seems like a wad of symptoms. For example, yesterday, this sort of swathe of reddish freckles, a lot of them, appeared on both my shins. It almost looks like a heat rash. My lower back aches. And I have some degree of either chronic fatigue or inveterate laziness. In order to be less unhappy, and reduce physical discomfort, I spend a great deal of time meditating, eating/cooking healthy food, doing medical stuff with both doctors and alternative medicine, stretching, taking supplements and medicinal tea, writing, and eventually, I hope, working. But you can't say these things in a personals ad... or can you? Low income 48-year old Buddhist Leo just learned a new phrase, 'medical menopause'. Otherwise, hopefully recovering from vaginal cancer, going hot and cold like a broken fridge in the tropics, soon to be unemployed, and blogging about it all. Care to swap suppositories?

Perhaps I sound bitter? I am not. Just not sexy. I'm simply unaccustomed to not being... hearty, and being in pain. I am not in a

lot of pain, and not all the time. It's a lot more work. Will I get used to it? I try not to complain. I need to look back over what I wrote before, the things I wanted to remember about life. My sister Kathy said last night that it seemed from this blog that I am not angry or fighting the fact that I have cancer, and that it seemed like that when she saw me. Geez, talk about adding insult to injury, at least I'm not doing that. As the Buddha said, like throwing a handful of dust into the wind.

May 29: **Exam, talk + brief maniacal planning**

Julie and I, just like old times, went to the health center today. I had an exam and chat with Dr K, who is a gynecological oncologist (an impressive ten syllables) and a surgeon. Dr O had suggested that because he is the only gynecologist in my posse of doctors, it might be good to get a follow-up exam with him. He was the first oncologist we met, in January I think.

The exam wasn't as painful as I thought it might be. He said there is a freckle-sized bit of scar tissue from the radiation which will probably never go away. Or it could be dead cells that have yet to free themselves. We asked a lot of questions. He is a really great communicator and uses a lot of metaphors, which I like. For example, he said the distant disease thing is like dandelions. If you pick the dandelions, other ones might appear elsewhere, you don't know until later. In response to my question about whether or not I will 'always' be considered high risk for cancer, he said it is all based on history, and I don't have any yet! As years pass, if my scans remain clear, the perceived risk diminishes. I asked him if it would be all right to ask him

questions after the PET scan, since Dr S is away so often. He said he would be happy to, but that from now on Dr S won't be away any more than anyone else and that "he would have been much happier if he hadn't had to leave last time". The plot thickens...

Strangely, the most helpful thing he said – in response to my asking about my current symptoms – was that many of his patients report feeling 10 years older after cancer treatment. I would say 15 or 20 years... But it made me feel better because otherwise I keep thinking all these symptoms are going to end, that I'm not supposed to feel so much older, especially when I get out of bed in the morning, stiff and creaking like the floorboards of an old house. When suddenly I need to take a shit and I fear I will not make it to safety...Those are the main things I suppose, other than sleeping, say, two hours more per night than I did a few months ago....Oh yeah, and the hot flashes are fucking out of control. I know it's a thing that happens to women of a certain age, but I feel that that is not the age I am at right now! I'm sorry to be a whiner. The idea of dying didn't bother me as much as the idea that I have aged 20 years (in some ways) in three months...

I feel a lot older than I did a few months ago, in ways that may or may not have ever happened without the cancer treatment. Of course without the cancer treatment I'd presumably be dead before finding out whether I was going to get arthritis in my hips 'naturally'... What Dr K said about his patients feeling older helped me accept this situation, and that feels better than not accepting it. (Then if it goes away, all the better!) On a related note, a couple of people have told me they didn't

understand the part in my last post about my sister noticing that I didn't seem to have any anger. Was it a criticism? No, it was a compliment, something she was impressed by. I thought that was obvious!

I had a very frustrating time at the pharmacy trying to get the barium, which I will drink the morning of my PET scan (tomorrow). I'm also going to start taking Estradiol for menopausal symptoms. I have three months' worth, I'm going to take it for that long and see how it goes. Misha suggested it. (My type of cancer is not estrogen sensitive so it isn't risky.) I also tried to get a blood test (Misha also suggested I get tested for Vitamin D) but didn't know I was supposed to fast, so have to do it another time.

I've got possible plans bursting out of my sides, but will not reveal them until after I've found out the results of tomorrow's scan, which will show 1) whether or not the known cancer in the bones has shrunk, stayed the same, or grown, and 2) whether or not there is new cancer anywhere in my body. I will know by around 5pm this Friday. I have felt for the last while that the cancer will be gone, and everything is fine.

May 31: **An hour in a shaking trailer**

A PET scan is a picture with a bunch of bright dots on it. The dots represent high metabolic activity, which means cells that are wolfing down glucose (sugar). Also the digestive tract will show up clearly because of the barium banana drink. The scan itself takes about 25

minutes, after allowing the radioactive tracer they shoot you up with to circulate. Being in the donut tube is actually pretty relaxing after you get over worrying about moving.

When I was sitting for half an hour letting the stuff circulate, all there was to look at was a machine of unknown function, and an EXIT sign on the door in front of me. I thought it strange that there was an exit sign in a room no larger than a closet. Probably a law? I remembered the signs in the London underground – they say WAY OUT, which is a much older way of saying it in English, whereas EXIT must come from Latin. It may seem like, and no doubt is, a strange thing to think about. For some reason I am interested in Anglo-Saxon (Old English) words.

Anyway, now that PET scans and CT scans are done at the same time, the collection of bright dots comes with a kind of map. One gets the impression that before this development the PET scans were rather hard to interpret. Also according to the self-identified technologist, exploratory surgery was much more common before CT scans. It was the only way they could see what was going on.

These days, people seem to have a lot of faith in pharmaceuticals, beyond what the chemicals might be capable of delivering... but for certain aspects of modern medicine, I am intensely grateful. At some point in the not too distant past, the medical response to my condition probably would have been to surgically remove the tumor, along with some of the rather important contents of my pelvis. Whatever health

problems I have now, at this point they do not involve carrying around pee and poo. Allah be praised!

My health plan does not have a PET/CT scan machine in San Francisco; it's contracted out, and you have to go outside to a trailer. From inside it seems to be in one of those San Francisco wind corridors, you could hear the wind howling, and when you stepped outside onto the little platform that lowers you down, you could feel the blast of an arctic gale. I'm going to cross that off my list of places I might like to end up working!

My confidence about positive results of the PET scan is waning a bit... The aches and pains in my lower gut and back, can I really know that the cause of them is not cancer? Ah, one more day to find out, I hope...

P.S. Since my last post, some folks have kindly reassured me about my own sexiness. In that post (about not being sexy), I was writing not about how I think I look or am being perceived, but about how I feel on the inside...

*

Song 2 (my animals)

18 March 2009

we are each a zoo

perimeter of cages

full of moving,

fur

these days my animals,

edgy,

restless,

realize where they are

rubbing

against the absence

of bars

they resound

still looks

like the same

zoo charging

the same prices,
the same morning,
still looks like
visitors, are staying
on the pathways mostly
trying to reach through,
leaving behind more or less
trash

the morning
looks the same

but here
surrounded by
blue night

without audience
my animals
sing

Expectations

from a talk about patience given to the San Francisco Gay Buddhist Fellowship, November 2008

I read a fascinating book a few months ago called ‘**Deep Survival**’, which studied why, in certain extreme situations, some people die and some people live. Mostly psychological reasons.

One of the points it made was that there aren’t any accidents. Systems aren’t perfect – they are guaranteed to break down. The people who can cope with changes in plans and actively work with them are the ones who survive. I think this principle applies just as well to our daily lives. For example, we can be killed by stress, much of which is self-induced.

One thing that isn’t an accident is sickness. Sickness is an intrinsic part of the human form. No one on earth has ever escaped it. Yet, our expectations are such that we expect not to get sick. We expect not to age. Expectations are mostly unconscious.

Pema Chodron had a story where she told her teacher that one of his students had relapsed and that she was really disappointed in him. He told her that her disappointment was a form of aggression, and that what he needed was kindness, not her judgments about him. Relapse is part of the system. It should be pretty obvious – we all go back on things we say we’re going to do all the time. Why be surprised?

Not being attached to results. Engaging. Doing what you can do, and letting it go.

June 7: Walking around SF with my old pal Jeff. A lady walking by wanted to take our picture in front of this heart, even though my hair looked like this.



June 2012: An adventure in how things are

June 1: **Brazil**

I've been feeling so happy. I visited Lisa Kee who lives at [Zen Center](#) now and had lunch there. (Not to mention some kind of caramelized macaroon at [Ritual Coffee in Hayes Valley](#). Mmmm.) I sat in our Center giving people their veg boxes, made \$67 selling stuff outside and chatting with people wandering by, then taught the drop-in introduction to meditation class. Ended up talking to two Brazilian personal trainers for an hour afterwards. The guy, who was doing all the talking since the woman didn't speak any English, said that I "transmit light". He had a very poetic way of speaking, possibly to do with vocabulary limitations, but some stuff came through. They had a lot of questions. I loved them. Not surprisingly, now I am thinking about visiting Brazil. I've had this kind of experience several times. You're trying to communicate with someone, and you have to keep it down to severe basics, but then you feel... love.

Later today, I get the news that will have such a huge impact on my life. In a way, I have gotten used to waiting, and have been mostly so optimistic and happy...

June 2: **"Sell your cleverness and buy bewilderment" (Rumi)**

At least this time I tried to act like my plans were tentative. I wanted to go to Mexico and do a 6-week intensive Spanish course before the

Order convention. A summer [Mindfulness Based Stress Reduction \(MBSR\)](#) course. Teach a series at sangha night on Love and Death...

A few days ago I asked Dr K if he would be willing to do some backup for Dr S, since Dr S has been away so much and my post-PET phone appointment was with someone I had never met. So about an hour before the scheduled phone appointment today, Dr K called me to talk about the results of the PET scan. The first thing he said was, It is not good news.

I did eventually ask about the cancer in my pelvis. He said that it is all completely gone. I remember Dr L saying he could get rid of the tumor, but that it was the “rest of it” he was worried about. There are 8-10 small metastatic tumors in my lungs. These were spotted on the CT scan two months ago, but were too small to evaluate. They have grown, and apparently lit up the PET scan. By the way, this isn’t called lung cancer, or even secondary lung cancer. It’s “primary vaginal cancer with metastases in the lungs”. I won’t know until Dr S gets back in 10 days what this means exactly, but chemotherapy for several months seems certain. Before ringing off I told Dr K that I had repressed hope during treatment, but this time I had had hope... But I suppose that was good because it meant in the interim I was in a much better mood! The last thing he said was that if he ever found himself in my situation, he hoped he could respond with the same poise that I have.

A few positives:

The disease has moved away from my nether region!

While chemotherapy isn't something to look forward to, at least it doesn't involve radiation/burning. As Julie pointed out, no more shitting razor blades!

My lungs are not in any pain, in fact I've mostly been feeling great the last few weeks.

My body responded very well to treatment last time, so it seems likely that it will do so again...

June 5: **Emergency Room**

Tong took me out to a real porker's breakfast at "Rudy's Can't Fail Cafe" in Emeryville. It was a great place (challah french toast!) except that my poached eggs weren't cooked well. Two hours later I started getting cramps in my upper abdomen, below my heart, which kept getting worse. Then I started throwing up, which I expected to relieve the pain, at least temporarily, but it did not. I tried being mindful of the pain, which definitely changed the sensation, but I couldn't do it for long. It's hard to relax with something that is trying to eject itself from your body. Or probably any kind of intense pain takes a lot of training to stay with.

I had put an Estradiol patch on my shin that morning. (Misha had suggested it for menopausal symptoms and osteoporosis.) We looked up side-effects. I seemed to have all of the following: cramps; flushing; nausea; reduced tolerance to carbohydrates; stomach bloating and

upset. I removed the patch at about 4pm. By about 6, after procrastinating some as I was dreading getting in a car, Tong took me, shaking, to the emergency room in Oakland, which was pretty quiet. Nurse Jackie wasn't there.

They admitted me immediately to my first emergency room that wasn't on television. First thing they do is see if they can rule out the worst case scenarios. For me that was an inflamed gall bladder or a heart attack. They drew blood and gave me a blue plastic barf bag, some Zofran (anti-nausea), and hooked me up to an IV. Before I got wheeled to a private room I had occasion to use the blue bag. There were people around. What was the alternative? I could barely move. I thought about actors acting barfing and how difficult that must be, to make a retching sound that seems to originate deep in your soul.

The pain was really rather amazing. I told myself that once I wasn't in pain anymore, I would really appreciate it. This is the second time I have asked for pain medication in my life. (The first was after a few weeks of radiation.) They don't exactly flow freely with the narcotics, do they? You have to ask, which makes me worry that they think I'm a junky just there to get drugs. Different people ask you to use the 'rate your pain 1-10' scale. I said 7 and 6. First they gave me Percocet (oxycodone), which did almost nothing other than making the room seem sort of weird. After I pressed the red button and asked for more, they gave me Dilaudid, which was awesome! It reduced the pain by about a third, but the thing is, you're so relaxed, you don't care about it anymore. The pain is not eliminated, it just stops being important! At

about 9pm, they said they could discharge me, but I was concerned that I'd just go home and start retching in pain again as soon as the drugs wore off. They gave me a drink and crackers to try and then they sort of disappeared. (I think things got really busy.) After an EKG because my pulse was so low (got down to 46), I was released at around 11pm, my pain at a '2'.

I think what I had was a combination of food poisoning and side effects from the Estradiol, plus maybe a troubled gall bladder. The doctor suggested I not use the Estradiol any more until I can talk to my doctor, which sounded excellent to me. When I woke up this morning, I felt fine, no cramps anyway. I've felt very happy, tired and kind of emptied out somehow... but very much appreciating not being in pain.

June 7: **Acronyms**

I spent the last few days walking around San Francisco having a great time with my old pal Jeff. Though we haven't seen each other hardly at all since we were teenagers, he is one of the few people on earth with whom I can totally relax.

My interview the other day at the Social Security Administration, in which the reincarnation of Franz Kafka would have felt perfectly at home, was OK. It was mostly about info gathering. Navigating these strange skies, one must know one's acronyms: SSDI (Social Security Disability Insurance) and SSI (Supplemental Security Income) and SDI (State Disability Insurance.)

I've been tripping lately on the fact that I've pretty much been happier since I got diagnosed with cancer (that is, much of the time.) Then I came across some **Stephen Levine** books. Found 'Healing Into Life and Death' at Julie's, then found 'A Year to Live' on our shelf. Levine works with people who are dying, and the way he writes about it is beautiful. Like so many of us, Levine at first thought of those who live as 'healed' and successful, whereas those that died failed to heal, but this view changed for him over time. He broadened his definition of healing. He says:

Each unique path led to a common goal... a deeper seeing of life, a deeper participation. Some took the work of deep investigation and the cultivation of such qualities as loving kindness and mercy as a lost child might, an open path through the woods... For years our work... has been an encouragement to open fully to this moment in which all of life is expressed, that the optimum preparation for death is the wholehearted opening to life...

Healing Into Life and Death

June 10: **A third opinion and more Kafka**

Various people have suggested I get a second opinion, again. Apparently the only organization in the U.S. that provides this service for cancer patients for free is in San Francisco. So I faxed off some forms to them on Friday. Social Security sent me a stack of stuff to fill out, work history for the last 10 jobs, which goes back a long time.

Also the summary from my interview had a bunch of stuff that was wrong. Not sure what matters. Might be starting to reach the limits of my capacity for paperwork. Next week I will see if R the social worker can help.

In general I have been slack on the healthy food and taking all the teas and supplements, etc. It all feels like too much work. And I have massive sugar craving! Strangely though, knowing I'm going to feel like shit very soon, I've been feeling great lately on all levels.

June 12: **Healing and choices**

After a few weeks of feeling very happy and energetic, the energy seems to have gone away. When I was thinking about jobs and things the other day, it occurred to me that my job now is to stay alive. Which means to take care of myself, which I haven't been putting as much energy into lately.

Had two healing sessions today. One was some restorative yoga with Dayamudra. She sets you up lying on the floor with various body parts propped up here and there for about 15 minutes, and over the time you get a very tangible feeling of certain body parts releasing tension. It felt great. The other was a session with Alan which is kind of hard to summarize.

June 12: **Healing and choices**

Lisa Kee, Padmatara and Dawn came with me to meet Dr S today. It was great to have them there, and recording it was very helpful too. Here are some things we talked about. First question: Dr O was

emphatic about cancer in the bones being incurable. Why did it go away? Answer: Gynecological cancers in the bone generally are not curable, unlike, for example, metastatic testicular cancer, which is very sensitive to chemo (90% survival rate). 25% of gynecological cancer patients (I think this means advanced stage) don't make it to five years, and that's often with continuous treatment. The cancer could still be in the bone, but it's not detectable now. With serial images every six months you would have more information.

Second question: Why is it important that I have 'vaginal cancer metastasized to the lungs' rather than 'lung cancer'? Answer: Treatment is based on cancer of origin. Because of this, there isn't great data about how well this chemo will work with vaginal adenocarcinoma. Have to just see how it goes. Carbo and Taxol are also used to treat lung and ovarian cancers.

Chemotherapy will be every three weeks (last time was weekly). After three cycles, I get a PET scan to see how it's going. If cancer is not responding, will need to change drugs. If after six cycles the cancer is still there, might take a one month break and start on different drugs.

Side effects: First week is fatigue, might have nausea but shouldn't actually vomit. Can use percocet or marijuana. (Wow, someone finally mentioned marijuana!) About ten days out, immune system at its nadir, so important not to be around sick people. If you get a (neutropenic) fever – 100.4 two hours apart, have to go to an emergency room. Suggest doing infusion early in the week so that doctors will be

around if something comes up. (Also, don't drink Kombucha tea, or live cultures. And don't take antioxidants during chemotherapy.) He said a road trip would be OK as long as you always know where the hospitals are, and you get out and walk every few hours to prevent blood clots. So, I've decided not to go to Montana. If something happened during my first round of the chemo, I would be far, far away from my doctors. I don't want to risk it. However, I will go to the retreat June 16-24.

June 14: **Cancer cures + I stopped eating sugar, again**

I've started drinking my fresh fruit/ organic whey protein shakes again – this morning with raspberries – which makes me feel better all day. I did have biscuits with my breakfast with the homies yesterday at the Pork Store (the name says it all) which are all refined flour... But I made hummus yesterday. Working on it!

I'm liking the online [Cancer Survivors Network](#). Though many of the stories are horrible, the people are very encouraging, and it is lived experience rather than data. I do not believe anyone who claims they can cure cancer. I don't doubt that by doing unusual things – and against all odds – some people completely recover. But I think it is very difficult to identify the exact reason for the recovery. And even if it were possible to say exactly why, one person's solution isn't necessarily another's.

All the 'cures' I have read about rely exclusively on anecdotal evidence, but fail to mention, well, death. So all these miracle

treatments with a 100% success rate for each of the hundreds of kinds of cancer have simply been crushed by the FDA? I might have confidence in alternatives if there were real studies, real data. Which reminds me of something Jack Donaghy says on **30 Rock**: “There are many kinds of intelligence. Practical, emotional. And then there’s, uh, actual intelligence, which is what I’m talking about.” (I love that show!)

Anyway, knee-jerk reactions from the different poles of medicine seem to kick both ways. It’s confusing to go to a healer who is against chemotherapy in some way. The acupuncturist I went to before my diagnosis seemed to think chemo is more likely to kill you than anything else. That’s one thing that’s so great about Misha Cohen. She really understands what Western doctors do for people with cancer and how to support that process while minimizing harm. And some oncologists are not sensitive to whether they may be creating a situation in which the medicine creates more suffering than it alleviates. Alternative treatments are not going to leave you disabled. The idea of ‘complementary’ medicine seems more useful than ‘alternative’, in that you hopefully get the best of both worlds without totally relying on either.

June 16: **Chemo appointment and support group**

My new round of chemo starts a week from today. Padmatara and I will leave the retreat early, which is sad for me. Viveka was encouraging us to come back. (The retreat ends Sunday.) I don’t know. I’d like to, but **Jikoji** is at least an hour’s drive from a doctor. I’ll go see Misha after the chemo.

Support group today – it was really good. Other than the emotional level of things, it's great to get advice and tips from people who actually say useful things. Here are some highlights, or anyway what I remember:

There were these really tasty-looking cookies. Shortbread with chocolate. I asked myself, This is San Francisco, don't these people know they shouldn't eat sugar? (I thought I might go mad with craving them, but I didn't.) I asked who in the group did not eat refined sugar, and almost everyone raised their hands, including the two social workers. And I noticed that no one had eaten the cookies.

Two women told me about the [Women's Resource Center](#) and also [UCSF](#) where you get free wigs and they help you pick one and they style it for you, etc. I might check it out, though I can't imagine wearing a wig, I am so hot all the time.

Chemotherapy with Carbo and Taxol: After you first get it, you're sort of drugged up so you feel OK. Then the crash of the white blood cells and you feel bad. Then the last week is sort of OK. So this seems to be the cycle. I'm so aware today of how much of a punch the word chemotherapy packs, just as a word. Will the reality hit as hard as the word suggests? I doubt it.

June 21: **The idea of an owl**

Don't let your throat tighten with fear.

Take sips of breath all day and night.

Before death closes your mouth.

Rumi

A few days ago my cousin posted a blurry but cool-looking photo of an owl he had startled in his backyard one night. The posted responses, except mine, were all along the lines of “Scary!” which surprised and baffled me. Owls are beautiful! What does a human being have to fear from an owl? Nothing. What does an owl have to fear from a human being? Lots. Mike’s explanation was that most city or suburban people fear animals, etc., in the country. And country people fear cities. Another friend told me about her son-in-law who had lung cancer. As he was dying, he would not speak of death, or allow anyone else to speak of it. Fear.

When Julie, Morgan and I went to Tanzania, I noticed we all had different fears. Morgan was afraid of insects (granted she was only 9 at the time). Jules got very nervous flying. I dove underwater with my snorkel and panicked. Who can really understand someone else’s fear? None of it, really, makes any sense. Sure, some bugs can kill you, people die in plane crashes, and people certainly drown... but there is no activity you can do with a guarantee you’ll live through it. It’s all irrational and yet... it’s real in the body, and must be paid attention to. I am grateful I’ve had to do this very little (until now).

I am possibly more afraid than I have ever been in my life. I am afraid of the super-toxic chemicals I am voluntarily taking intravenously on Friday. (Various people’s anti-chemo sentiments add more confusion.) I’m afraid that this cancer situation won’t end up being finite like I keep

thinking it will be. Do I truly have anything to fear from chemo? Well. Maybe. Probably? I won't know how it is until I do it. As with cancer itself, there are a lot of totally different kinds of chemotherapy. The word is strongly evocative. An image perhaps of Meryl Streep, skeletal in a hospital bed. But overweight people have a cancer advantage, a little known fact. (Actually, not true except in the sense that we can lose weight without looking like an animated skeleton.) So discomfort/pain and death are the possibilities. Death at this stage very unlikely. Worse things, things I can't even imagine now. It's all just ideas right now. The reality is not known. It's the idea of an owl... or a rattlesnake.

A retreat is a great place to deal with fear, and everything else. The theme of this retreat was the [Heart Sutra](#), a great love of mine whose subject is reality. What is. Fear. Mental projections. Perfect. Also terrible, because you feel more on retreat, when you pay attention. But that's also what allows it to change. I led a ritual to [Perfect Wisdom \(Prajnaparamita\)](#) Wednesday night, which I really enjoyed. Among many other things, people chose and read relevant teachings, including a flash mob style Rumi poem. Listening to the readings, the whole thing really, was healing for me. I felt my fear leave me... not really leave me, but relax the grip on my heart. Here is what I read (from [Osho's commentary on the Heart Sutra](#)):

You think stones are food and you eat them; then you suffer, then you have a great stomachache. But if it is real food then you don't suffer, then you are satisfied. Suffering is created by ideas that don't go with reality; bliss is created by ideas which go

with reality. Bliss is a coherence between you and the truth; suffering is a dichotomy, a division between you and the truth. When you are not moving with truth, you are in hell; when you are moving with truth, you are in heaven – that’s all.

I want to think of chemotherapy as an adventure. An adventure in how things are.

June 23: **Information onslaught**

Yesterday started with a pill as my days often do. This time it was cetirizine, an anti-histamine to help prevent an allergic reaction to the chemo. Padmatara and I were at the Infusion Center by 8:30am. We got C the oncology nurse again, which was great. Started with a 15-minute infusion of something that sounded like pepsis and an anti-nausea thing which I think was dexamethasone, plus two anti-nausea pills. Then wait 15 minutes and start the three hours of Taxol. They gradually increase the rate while looking at you to see if you’re having an allergic reaction, which apparently involves turning pink. I did not turn pink, which surprised me, since I often do. Then the last half hour is the Carbo. Toward the end the injection site on my hand started to ache. The Carbo contains the heavy metal platinum, which is why food starts to taste weird/metallic. So I am no longer golden, I’ve gone platinum, for a while.

Side effects of the three anti-nausea drugs include constipation which I am kind of looking forward to. (Or will I be saying, like [Dorothy Parker](#), “What fresh hell is this?”)

Other than anti-nausea pills, I was also prescribed a filgrastim injection, which I am supposed to self-inject for a week starting on Day 4. It's a growth hormone for bone marrow stimulation, to counteract neutropenia and reduce the risk of infection. Unfortunately it is also known to cause bone-crushing pain. There are a few things that can help with this. Dr S said 50% of his patients who take it do not experience bone pain. There's also vitamin B6, and powdered Glutamine, an amino acid, that can help.

Having just gotten off retreat and sat in a small room for six hours, driving across San Francisco seemed very strange, but we made it to Misha's. She gave me loads of herbs (pills) to take, the regimen changing with the different phases of chemo, and a new treatment plan. She has seen people in terrible pain from the filgrastim injections and asked if I could try not taking it but get blood tests often to make sure my blood counts are OK. I'll talk to Dr S and C about this on Monday. If they don't go for it I'll have to start with the injections that day. Anyway, I had a treatment from Misha and felt great afterwards.

June 24: **Cat naps**

I've come across a couple of writers I like who touch on the subject of cancer. One is Stephen Levine ([Dharma Punx](#) author [Noah Levine's](#) father). The other is [Cary Tennis](#), a local who writes the advice column "[Since You Asked](#)" on Salon.com. Looks like he had a cancer ordeal that lasted seven weeks, though it was written in 2010 so I don't know what's happened since then. Anyway I found something he wrote, [Having cheated death, I feel alive](#), that I related to:

Oh, I could take it or leave it, life, I thought before this happened. What's so great about this beating heart, these heaving lungs, these eyes through which the world enters and signs its name? But threaten to take it away and see how I change: What pleasure in every heartbeat and every breath! What complexity in the color of a rain cloud! O gods of chlorophyll and proteins: to almost lose life and then to get it back! How bright this earth now! How beautiful these faces! I stop at every stop sign and look around to see what new miracles there are.

I have to confess to things seeming not quite as miraculous for me, six months into it. However, I'm still doing all right, so far. I'm learning how to take care of myself better on multiple levels, ask for what I need, not expect understanding in certain ways, appreciate my life, and not get too angsty about stuff.

Other than two sun hats, the hats I have are going to be too hot once my hair falls out. I will get a wig I think (special occasions?) but wigs are even hotter! I will probably need to get some lightish scarves. I may just try the bald look too, we'll see. I see there is lots of (upbeat and less upbeat) tutelage on YouTube. You sorta want to make sure the video has a bald person, because scarves on heads of hair look different.

June 26: **An actual cancer patient**

It occurred to me that before becoming one myself, I had never seen someone on chemotherapy except in a movie. They usually look like

they're about to die, and they usually do. Dr J, medical oncologist and director of thesecondopinion.org, called this morning. So went my second second opinion. As last time with Dr C, he said I am getting the standard treatment considering the rarity of my condition. I didn't get much new info. He commented on what a good attitude I have. What are the other people like that he talks to? I have no idea.

I got my award letter today for disability which will start in August, so I need not worry about being a burden on anyone. It's less than what I was making working for the Center, which was very little... still, it is a great relief. So far the pattern seems to be that I feel all right in the mornings, positively energetic even, then crash after that. This evening on a walk with Padmatara, everything was surreal – the blooming plants, the architecture, the [Led Zeppelin](#) song blasting from a parked car.

Food on Mars

Dr S called this morning and said it's all right not to do the shots and just see how the next blood tests look. Without the shots, there is a 20% chance of neutropenia, which I think means neutrophils are below a certain level. He said something about an 'Area Under Curve' of 5, whatever that means... Anyway, it is a huge relief. Misha was pleased to hear it too. She said if the counts are low we can up the dose of Marrow Plus (an herb blend) I am taking.

I managed to get to [Rainbow Grocery](#) and among many other things buy two big Turkish figs. But then, it was as if I had gone to Mars and

eaten a fig. Not a real Martian fig perhaps, but one you might find if you were with [Doctor Who](#). I hope that's sufficiently descriptive. Everything tastes only slightly like itself.

For lunch I made sprouted hummus (which actually takes very little effort) and cucumbers. Also had some skyr, Icelandic-style coconut-flavored yogurt, in honor of my sister, brother-in-law and step-mom who are now in Iceland. It was good, and as close as I'm going to get to ice cream. Later I made miso soup with soba and a few beet greens. So I seem to be getting back into the mode of self care.

I feel weird but it's hard to say exactly how. My hips seem to be aching more, which is either because I'm not moving around enough, or because the chemo is making my arthritis worse, or both. I did manage to take a little walk and do some yoga today. Seems like it's going to be all about the digestion, finding healthy food I can manage to eat, lots of liquids, and getting enough rest and movement.

June 28: **How much to reveal?**

Went to a [Feldenkrais Restorative Movement](#) class at UCSF this morning. It was fantastic! We did almost nothing, which is kind of the point. It is an awareness practice involving very small movements. At first I felt all tight and trying too hard. Forty-five minutes later, much more relaxed and spacious.

Shall I reveal what happened afterwards? Well. I pretty much diarrhea'ed myself before I could get back to my house. Last night I had rich and slightly spicy pad thai, which blasted through me all

night. I thought it was done. Must remember to use the toilet every chance I get when I am out, especially before I get in the car! Felt pretty rough all day, hardly got out of bed. How I feel, what I can do, energy level, gut situation, seems to change quickly. This is Day 6 of 147 days of chemo effects, at least. My first round of treatment, during the radiation and chemo, I was mentally prepared to die. It still feels important to be prepared to die. This time, though, I am planning on living.

June 30: **Uncomfortably numb**

While horking down popcorn yesterday watching a movie with Cull about male strippers, my feet and hands started to go numb – also known as neuropathy – a side effect of the chemotherapy I was warned about. I think all they can do about it is reduce your dosage next time, or change drugs. If it gets too bad or goes unchecked, the nerve damage can be permanent. All I'm supposed to do about it is let my doctor know, but these kinds of things seem to happen only on weekends.

And I started feeling weird, something but not quite like my body being wired up and weirdly drunk at the same time. With random pains coming and going, and chills. My temperature was a little high. For a few moments I thought: Oh my god, I cannot take this for five months! Then that thought kind of merged into now, which can only be itself. After lying down for a while, and 600 mg of ibuprofen, and beef wonton soup, the elixir of the gods, I felt fine. I might try marijuana at some point and see if it helps anything.

Cull made some chard from one of my new cancer treatment oriented cookbooks by Rebecca Katz today, very good. I will start eating less fruit. It's so awesomely tasty right now but it's pretty much a laxative, and has a lot of sugar. I've been walking every other day, and not doing very much yoga, alas. Also I looked at the chemo sheet nurse C gave me and found sun sensitivity, unlike what another nurse told me on the phone the other day. You know how when you ask someone a question, and you can tell they don't know, but that they're going to answer anyway? So, sunscreen.

Good god, endlessly talking about food and my health etc. is so boring. But I carry on, it's all I got. How am I? I can't answer that question in a general way. I feel great when I wake up. Before I lay my head down again, a kind of fog will slowly settle in, and my body will do weird things which will then change. Capped off the night watching some Louis C.K., which was great.

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Memoirs of observer and observed

25 March 2010

The song I have come to sing
remains unsung to this day.

I have spent my life
stringing and unstringing
my instrument.

Rabindranath Tagore

Sitting here together, we are each watching the mind, feeling the body, living the senses. These aspects of me respond in various ways to this situation, in which we go against aeons of evolution.

When you first start, and later too, you're mostly as-if. Everything is buzzy. That's why you don't want to do it, to go against. There are disturbing creaking sounds. The body cries out to be heard, like a baby that keeps pretending to be hurt.

But everything's set up for this now. You go against – which means you just stand there, you get swept away, you recover and stand some more – then the river gives up and starts flowing the other direction. The senses lose their hunger and become a very large orchid that flourishes and dies, flourishes and dies. Hours pass.

Still, my knees send their pain message... but why am I separate from my knees? Why so far away? It creates opposition. Are my knees

trying to pick a fight? Why is the situation like this? Not much happening in the way of answers.

*

A bright afternoon, outside, loving the tree stumps.

Things aren't more colorful or happy or what you might think of as spiritual, in fact there is a trim of sadness to them all. But they are nonetheless quietly fascinating, and my mind is a sea sponge, completely drenched with lucid clarity.

When we observe something, especially something about ourself, there is usually a sense of an observer as well as what is observed. Sometimes what is observed seems to be the more 'real', sometimes it's the other way around. Say you notice there is thinking. Where is the energy, where is the life force as it were? Maybe the muscle is in the thinking process, and whatever is noticing the thoughts seems relatively weak. Or maybe what notices is vast, and the thoughts are just tiny blips in the spaciousness.

Now, here, the observer is so large and lucid and absorbent that it sort of envelops what is being observed. Both are in a way exactly the same; they are both smaller, and more huge, than we think.

I see a motion picture of myself doing the next potential thing: climbing up that tree. My next move is projected before me, as if I am living a movie that shows short clips of my thoughts about what to do next. I can hear electricity. It's like being a child again, or an acid trip... but

really it isn't like either. It's further inside, and it's the result of conscious effort, trying to stay upright in the stream, which makes it essentially different, subtler and deeper.

I begin walking and notice how soft the ground is. I think, I'm killing things here. Jains sweep their path before walking to remove insects, to reduce death. I walk a short distance; there isn't really a trail. When I turn around and stop, I hear leaves rustling. There is a small skink thrashing from side to side. I must have stepped on it under the leaves.

It's sad. I watch her thrashing. I wonder about staying with her 'til she dies. But what if she doesn't die? What if she takes a long time to die? I'm not going to squat there for 12 hours. Or even one. Am I heartless or... sentimental? Or both, or neither? I send loving kindness to the lizard.

I contain the spectrum of responses and points of view. Each moment is very clearly either tragic, or insignificant. I cannot tell which.

*

Now I am drinking beer with an old friend and it is nice. I start to get a minor version of the spins, which adds another point of view. I realize everything that I want is to be aware in every moment. But caught in the habits and complexities of daily life, the moments are lost, in movement mistaken for meaning, in production, in resistances that rise and fall, noticed and unnoticed, in the idea of time that rules my

days, in trying to put a patch over the vacuum, in the essentially painful chore of being someone, needing.

I guess I'm still seeing some things, seeing that this is the way it usually is. But now, it hurts. The observer is a shrunken head. The observer is no longer the world's largest sea sponge. Habits are a blue whale with a barnacle on it that observes.

I notice that when I am reading emails, emotions pass in waves, and I usually do not take time to acknowledge them. Things get tangled up. People shrink to fit inside my screen. My affection for them shrinks as well, unless I pause.

I do not like the idea, the certainty, that I will subsume myself again in the world of habits, and wait for the next retreat to release myself. But that is how it is. Not so black and white, but rather, dark gray, off-white.

July 28: Did I say anything about my talk at the center? It was intense for me, but I did enjoy it.

Photo, Kathy Cullen



July 2012: The emotions of statistics

July 5: **A good day to have cancer**

Mon Dieu, as the French say, what a great day I had! I ate like a cochon... and I felt great. Spent the morning at [Lands End](#) walking around and catching up with my wonderful friend Lena who I haven't seen in a long time. Then a deluxe lunch at [The Beach Chalet](#). I really splashed out, having iced tea and a decaf coffee. Not to mention the duxelles and mache. Can you imagine the debauchery?

The lady who teaches pilates for cancer patients at UCSF called me back – she was encouraging me to keep up the exercise. She said more and more research is showing that exercise makes a huge difference. (Come to think of it, not sure if the difference is in tolerance of the treatment, curing cancer, or both.) In terms of how I feel, it makes a huge difference. It seems like the less I move, the less I can move, and the more I move, the more energy I have. To an extent.

Then we picked up Po, dropped Lena off downtown and headed for Misha's, where poor Jerome had to give another moxa tutorial, this time for Po (last one was for Kathy, but we both then forgot about it). They want me to do it every day. It's the same principle as the needles, but applying heat instead. It's like holding a cigar that smells vaguely of marijuana (but is mugwort) an inch or so away from the skin at certain points in my abdomen and feet. The heat feels great.

July 6: **My hair's falling out**

I took a walk up the hill with Dawn this morning, and after my shower, I brushed my hair forward and a bunch of hair fell out. So far I have managed to avoid looking like a cancer patient, because I look healthy, and I am fatter than you expect a cancer patient to be. But the sight of a bald woman pretty much screams “cancer patient”. I shall have to get used to that. I’m very focused on myself, which I sort of have to be. I’m also thinking about using my spare energy to think of others more. I told Nancy from Nancy’s List (a really great org that among other things offers free sails around the bay to people with cancer) that I would help with looking for funding. Hopefully I will have the energy next week to spend a few hours at the [Foundation Center](#) downtown.

Though my hair has started falling out today in great swathes, and I am very tired (of course it’s also 1:30am), I have felt remarkably well for the last week or so. Paulette was here doing a lot for me – laundry, cleaning, cooking, errands – it was awesome. I’m taking her to the airport in a few hours. House will be empty for just a day or two, just me and the kitty before Jeff arrives.

July 8: **The emotions of statistics**

I haven’t had anyone tell me I am going to live, or that I am going to die. Or that the treatment will work, or not work. Or any odds about anything. As I have said before, estimates based on studies are to help doctors make decisions about treatment for individual patients. They are not relevant to prognosis for a particular patient. Denise, who

had breast cancer twice, said the other day that the prediction for her was 98% success rate. She ended up in the 2%.

But we rely on these numbers. On an almost instinctual level, high numbers (suggesting positive outcomes) are relaxing. Is it more helpful to focus on the positive, to tell oneself that one will be part of the statistic that lives/thrives/heals? I suppose it depends on how one does it. "Positive thinking" can be avoidant, and aggressive. I don't try to think positively, or negatively. It's more that blanks automatically get filled in.

I realize now what I think, that the current chemo will take care of the cancer in my lungs, and I'll be done with it all after that. There is virtually no basis for this view. True, I responded well to treatment last time. I take good care of myself. But the outcome is totally unknown. I don't even have any odds to trick myself with. I think it would be harder to do this if there were numbers: 30% chance of this, 70% chance of that. I fill in the blanks in my own way, mostly not consciously. And I fill them in in the way I do probably because on some level I still don't think of myself as someone who is a candidate for cancer. This whole ordeal has got to be just a blip on the screen of my life..

My thoughts about it have become more subtle in the eight months since my diagnosis. At first and for some time, it was: I'm either going to live or I'm going to die. I was not aware of other possibilities. The subsequent dichotomy: if I live, I'm either going to struggle with

cancer/treatment my whole life, or not. After treatment was over and I wasn't recovering quickly: Will I live without cancer, but be disabled by the treatment? Then most recently, I had a great deal of fear about what chemotherapy, not cancer, would do to my body. There's a lot of fear to deal with, all to do with future possibilities.

Denise said she takes time every day to acknowledge fear. I think she said in the shower after swimming, she lets it all happen. Then she puts it in an imaginary box until next time. If fear comes up during the day, she tells herself to wait for the time to open the box. A creative way to deal with fear. All I do really is just try to be aware of thoughts, particularly of speculation. What if this happens? What if that happens? Slowly I see myself creating scenarios, see the suffering in this, and let them go. I'm getting better at not knowing and the freedom that brings. There's always a new thing not to know.

Then what I am afraid of comes.

I live for a while in its sight.

What I fear in it leaves it,
and the fear of it leaves me.

It sings, and I hear its song.

Wendell Berry, from 'I go among trees'

July 10: **Continuing hair trauma**

You can't tell yet that my hair is falling out. I mean, it still looks like I have a full head of hair. But it's falling out into my eyes all day. I have

lots of very fine hair. At some point it's got to run out. Fact is that I am dreading my imminent and mandatory bald cancer patient costume. And I will get used to it. I've had a good run for eight months with a full head of hair!

Did my community service for [Nancy's List](#) (looking for potential funders at the Foundation Center) and while I was there got an email from Nancy saying she didn't really need me to look for funders after all! I did find a few places that might give me a writing grant. It was fun doing something different. I'm also thinking of appealing my Social Security which starts in August (that is, getting the lawyer to help me get the back pay going back to January).

Starting to feel very jetlaggy, spacey. I think my version of the 21-day cycle is feeling ass-kicked toward the end. Today is Day 19. Must-have afternoon nap. I made a complicated schedule today of all my changing pills etc. I take during the 21 days. In this phase of six days, I take 30 per day. I'm keeping up the walking every day.

July 11: **Who's the fat old bald man in the mirror?**

I hasten to point out that of course there is nothing wrong at all with old men. The problem is that I didn't think I was one. Until today. Shantinayaka kindly buzzed off most of my hair this afternoon. It was starting to look weird, and seeing bits of my hair everywhere – for example, on my computer screen right now, or in my food – was driving me crazy. When I buzzed my hair 15 or so years ago, you could not see my scalp. Now I have around 20% density. It will be

easier to take perhaps when it is all gone, which I imagine will be soon. I have an appointment through the American Cancer Society to do a wig fitting tomorrow morning. Or, as it is I thought I might enjoy being bald. There's still plenty of time for that.

The nice thing about meeting Dr S is that chemotherapy becomes run-of-the-mill. It's totally normal to him, and he's funny. You deal with the symptoms and make it work. We talked briefly about my emergency room visit. I mentioned that Tong ate the same eggs and didn't get sick. He did not think that meant I was more immune compromised, could be just that the bites I took had bacteria in them and his did not.

Blood counts came back and look good. For example, normal range for neutrophils is 41-81%. Mine is 62%. White blood cell count and red blood cell count are on the lower side but still in normal range. I wish I could see what they would be if I weren't taking all these bloody pills!

July 12: **Things to do for your cancer patient pals**

I've heard a lot that friends and family of people with cancer can get frustrated because they want to help but don't know what to do. I was thinking of making a list of idea... BTW, if someone says to me, Let me know if you need any help, they will never hear from me, because I don't know what they're offering, or if they're just being polite... and it's difficult to ask for help anyway. I am too tired now to write this list. So here's a poem you may enjoy in the meantime:

How To Behave With The Ill

by Julia Darling

Approach us assertively, try not to
cringe or sidle, it makes us fearful.
Rather walk straight up and smile.
Do not touch us unless invited,
particularly don't squeeze upper arms,
or try to hold our hands. Keep your head erect.
Don't bend down, or lower your voice.
Speak evenly. Don't say
'How are you?' in an underlined voice.
Don't say, I heard that you were very ill.
This makes the poorly paranoid.
Be direct, say 'How's your cancer?'
Try not to say how well we look.
compared to when you met in Safeway's.
Please don't cry, or get emotional,
and say how dreadful it all is.
Also (and this is hard I know)
try not to ignore the ill, or to scurry
past, muttering about a bus, the bank.
Remember that this day might be your last
and that it is a miracle that any of us

stands up, breathes, behaves at all.

July 14: **No need to be nervous**

I was pondering this blog today and realized that I write certain things here for certain people, but don't actually mention that. I may be thinking of one person when I write... then someone else usually asks if I was writing about/to them! Like a very close friend – after reading yesterday's entry – asking me if I don't ask her for help when I need it. This happens in person, too. Sometimes I can't anticipate what someone will take personally, I assume that everyone to whom it doesn't apply will know that. Then in hindsight, it seems obvious that they wouldn't, because things that are obvious to me could well be obvious only to me... this isn't quite coming out right...

My point is that sometimes I have zero emotional intelligence. I write very directly, and regularly do not anticipate any subtlety in how it may be received. I do this not because I want to be harsh, but because I am completely unaware that it may be taken as a critique. So please imagine I am saying the words in a kindly voice. If I make a suggestion, I am sincerely trying to be helpful, and if it is not helpful, please feel free to ignore it, or tell me how it affects you, or read it again hearing it in a kindly voice and ask yourself if it really applies to you. There is no need to be nervous about saying the wrong thing to me. I love you for many reasons including that you are reading this. I wish I were able to always communicate that, such that there could never be any doubt.

As you may have gathered, having clumps of hair falling off my head and making my scalp all patchy and cancer patient-y has been

disturbing. Apparently I have become very attached to seeming healthy, even though technically I am not. After eight months of normalcy (not a real word), my head suddenly became a shorn radio blasting to everyone that I have cancer, that I am possibly even a modern grim reaper. It freaks me out, and my scalp is also starting to hurt. I think shaving it all off will help. Then I can just carry around a picture of the Pope and tear it up in an emergency.

In order to spend the night at Julie's I had to sort out and pack masses of things. Head coverings including for sun. Clothes for a 20 degree heat increase, laptop and book of notes for blog. Erg. Keyboard, glasses. And I forgot the rather crucial Ativan and psyllium husk. Camera battery charger. Book. Flip flops. Hiking shoes, but I think I forgot those too. Water bottle. Eyebrow pencil. Calendar. Snail mail. Julie offered to help me gather my things, I really should have taken her up on it.

Factoid: The widely-used chemotherapy drug Taxol was discovered on my birthday! Exactly one year before the day I was born: August 21, 1962.

July 17: **Chemical cocktail**

My body seems to be raging with chemicals. Mostly of the pick-me-up variety, but there's the occasional wah-wah, jet-laggy spaciness. And the odd aches and pains, and numb toes. And it takes me a long, long time to go to sleep, unless I take Ativan, which I have been every

night (except for when I was at Julie's and stayed awake in bed until 5am!) Still, I would rather be energetic than tired.

Had a great time yesterday catching up with my old friend Sara who I haven't seen in about ten years. She's just finished nursing school. I noticed that I told her how I really trusted my doctors, and also how my doctor has wanted to give me some serious medications twice, when upon further inquiry it seemed that I didn't really need either of them. After my first treatment, he wanted to put me on Pamodrinatate to prevent fractures, but when I asked if he thought I was particularly vulnerable to fractures, he said no. Then after the second treatment/ chemo started, the Neupogen shots to combat neutropenia, even though my blood counts have been very high, and the risk is only 20%. Sara mentioned that the medical profession just wants to give you loads of drugs, which certainly seems to be true.

I'm giving a talk next Weds at the Center about my experience of having cancer. It's so personal I don't quite know what to say. Thinking of themes: Preciousness of life, impermanence, anxiety, and love...

July 19: **The 18-week marinade**

On Friday morning when I asked C if it was time to start the chemo, he replied that I needed to marinate a little more first. And the marination has continued. Have felt so very drugged... and now coming down, way down. Today I am far inside myself, dreamy. I am seeing people through a telescope.

I was reflecting about how my Buddhist practice has changed. Now it seems to be all about noticing and reflecting on my mental states, talking with people, and writing. I used to do more than that. I used to meditate every day, and I used to map out the future. There was always, there always seemed to be, somewhere, a future, or at least an imagined future perfuming the great matter of life and death. But then any degree of certainty and the future disappeared. And I thought for a time that it was possible to be neutral about that, to only not know. I see now that I was still filling in blanks, to some degree – mostly with death.

Now I am assuming that the cancer in my lungs – or must I use the cursed word nodules? – will be crushed by the cytotoxic tsunami in which my body now marinates... and if it doesn't, angsty about that now will in no way prepare me for it. Sure, there's not knowing: I most certainly do not know. But there is always some sense of the outcome, it's there, it affects things, I don't even have to think about it. I don't think a positive attitude necessarily makes positive things happen, it just makes everything feel like less of a thorn in one's flesh.

Don't know if I can give the talk next week. Feels like getting into a car accident and trying to give a talk as you're flying through the windshield... Danamaya suggested just doing what I can, that that is enough. She is probably right.

P.S. My eyebrows hurt today. Which I'm assuming means they're about to fall out.

July 24: **Side effects**

Chemotherapy is supposed to make a person skinny. In our minds. In the minds of medical people, that's the last thing it's supposed to do. The skinnier chemotherapy makes you, the more likely you are to die, because it's predictive that you cannot tolerate the treatment. Which is maybe why we associate chemo with skeletal people and death.

People are often surprised that I can eat. Kathy referred to me as a gourmet cook this morning, because I was eating eggs with chard and manchego (Spanish cheese), and a pancake (made from an organic mix) with fresh currant sauce. And last night I made up a recipe for wontons: minced water chestnuts, garlic, vegetarian sausage, and oyster mushrooms. (Although using our shitty teflon pan wrecked some of them.) I like cooking when I have the time and energy, and stuff on hand. I often do not use a recipe which makes it a bit hit-and-miss.

The other day someone grimly commented that a lentil soup I had made looked "healthy". I've noticed that people who use that designation seem to be in some way unfamiliar with vegetables... or at least not on speaking terms. It kind of feels like they're insulting the food you made, like a fashion designer calling a pair of shoes "comfortable".

July 28: **Tripping and nose hairs**

I've had a runny nose for some time now and was wondering if I have a cold, though it didn't seem like it. So the big news is that this

happens because, apparently, I don't have any nose hair.

Revelation? I'm in Fresno for the weekend with my three sisters (in the sizzling Central Valley of California, three or so hours' drive from San Francisco). Can't sleep. Laura can't sleep either. She's scratching one of those more involved lottery tickets with a quarter. And we talked about my mom who has Alzheimer's; it's terrible. Nine milligrams of melatonin later, slumber...

I've been tripping a lot lately. Not in the usual sense of the word (when I use it) of strange or interesting. In the cancer pilates class yesterday, which was great, we did a few balancing type exercises. Generally I have good balance. Then getting up to go to the bathroom I tripped and almost fell over. I can only guess it's from the numb feet. I'll tell Dr S about it on Weds and maybe he will reduce my chemo dosage. I'm getting more tired. It's not exactly sleepy, and it's a bit wired at the same time. It causes craving for coffee and sweets (but not too bad). I'm getting used to the hair situation. Laura said to me yesterday that I am beautiful and it doesn't matter what my scalp has on it, or something like that. It was nice.

July 30: **Spinning head**

My process of becoming a private preceptor is going well. For those of you who aren't familiar with this process it's not that easy to explain. The short version is that once you've been ordained for ten years, someone can ask you to be their preceptor, which means that you will ordain them when they are ready. It involves a lot of people agreeing that it's OK for you to do it, that there aren't any major or unresolved

conflicts with any Order member (or anyone else involved with this Buddhist community). And you ask those that know you best to write feedback, areas you are skillful in, and areas of challenge. There are some more steps to come but so far it has been a wonderful process.

I drove to the health center twice today. Fasted overnight, went to Feldenkrais/restorative movement, had pre-chemo blood drawn this morning, and met with Dr S. Wanted to go to the art in recovery thingy as long as I was down there, but came home and fell asleep instead. Also gave informal cancer talk II at the Center tonight after meeting someone for dinner and getting a tarot reading! My head is kind of spinning. Need to figure out a way to get some more down time.

My Time

by Leonard Cohen

My time is running out
and still

I have not sung
the true song
the great song

I admit
that I seem
to have lost my courage

a glance at the mirror
a glimpse into my heart
makes me want
to shut up forever

so why do you lean me here
Lord of my life
lean me at this table
in the middle of the night
wondering
how to be beautiful

The preciousness of life

From a talk on creativity, February 2010

One aspect of creativity is appreciating things, being in touch with the preciousness of life. Nietzsche said that “art is essentially the affirmation, the blessing, and the deification of existence.” This is very interesting to me personally. I think I naturally have a great love and appreciation of the preciousness of life. I also have this deep kind of hatred of life. I don’t know what is underneath what. I would like to think that the love is underneath the hate, and I think the odds of that are pretty good, but just based on my experience, I do not know for certain. I just know that I get overcome occasionally, sometimes only for a few seconds, with a very bodily sense of I do not care, there is no point, everything is, if you’ll pardon the expression, completely fucked.

Part of my process is accepting this aspect of myself, not trying to change it because I can’t, although it may well change. I don’t need to make it into a problem, just know that this is part of what informs the way I experience or interpret life. And appreciation is also part of that.

To see the preciousness of life, we have to stop focusing on what we think is wrong, and obsessing over how to overcome what is wrong and get our needs and standards met. We have to see suffering for what it is, see into the heart of suffering, see it even if it is covered over or cloaked by an angry or indifferent face. This is part of the reason our life is so precious, because of all the difficulties, and the fact that

whatever good conditions we may have today may not be here tomorrow.

Seeing the suffering in life and not turning away from it. From our own suffering and the suffering all around us. Seeing the suffering in our entrenched relationships and working on them. Which are possibly some of the most 'reactive' connections we have, perhaps with people in our family.

This is one way that we free up creative energy, by engaging with and untangling our tangled-up human relationships. I think we all have them. (If you don't have them, then you perhaps have a lot of energy available!)

Wallace Stevens wrote: "The way through the world is more difficult to find than the way beyond it." Very true, very beautiful. As we go through the world we see how much difficulty there is, we see deeply how precious this opportunity is, how precious this life is. We feel it every day. How lucky we are, and our pain, and what is made by the combination of the two.

Trungpa agrees: "Genuine inspiration is not particularly dramatic... It comes from settling down in your environment and accepting situations as natural. Out of that you realize you can dance with them." He also says that "Genuine art – Dharma Art – is simply the activity of nonaggression." Fascinating. What is meant here by aggression? Aggression is reactivity. Aggression is unaware stress, confusion,

suffering, shutting down toward life, not seeing life, not appreciating life.

Trungpa also says, “We have to be honest, real, and very earthy, and we need to really appreciate things as they are.”

I felt a small shift along these lines the other day when I felt locked in stress and went for a walk up the hill and saw three beautiful Siberian huskies. There was a lot to appreciate before I saw them but after I saw them I was more able to appreciate everything else.

Non-aggression means whatever is not aggression, which suggests love. Which brings to mind that saying, “The creative mind loves where there is no reason to love.” The creative mind takes Rumi’s advice, who tells us that “our task is not to seek for love, but merely to seek and find all the barriers within ourselves that we have built against it”. So this is part of the work, the play of the creative mind.

We don’t ordinarily think of associating Buddhism with love. It has kind of a rational, mental connotation in the west, where many of us fear hocus pocus. I think we need to start associating Buddhism with love. Ideally people who meet us would automatically start to associate Buddhism with love just by how we are.

August 8: What the I, Robot robots looked like.
Sometimes I'm surprised at how north euro-looking I
am.



August 2012: These are not obstructions to enlightenment

August 4: **“Don’t worry about flaking out”**

Savanna came to SF today for a short visit, and went to part of chemo with Padmatara and I, and acupuncture. Afterwards we had croque monsieurs with mushrooms at [Tartine](#). We arranged to meet at 9am tomorrow before I head to a play and she heads home to New York. She said something like, “Don’t worry about flaking if you’re too tired or change your mind.” I am very unlikely to cancel but it was delightful to hear that, if I did, she would understand. It’s true that I have spent a (relatively) colossal amount of time with people for the last... yeah, I don’t know, must be at least a month or two now. I have enjoyed all of it, but it is a lot, and sometimes I feel almost overwhelmed. (I have all day Sunday unscheduled so that is great.)

The chemo session was unremarkable, except no C and we were with other folks in the bigger room. I should have asked for the private room, but my chemo sessions are long now, minimum of five hours, so getting a free room will be more of a challenge. Actually it was interesting being with other people. I was there the longest. Different people cycled through the other chairs. And they halved the oral dexamethasone – Dr S must have talked to them – and it was way better. I am prone to some kind of sub-clinical mania... or maybe it’s better to say just occasionally high-strung. In any case this chemo and

accompanying Rx greatly amplifies that and I was starting to find it kind of torturous. Talking to the social worker the other day, for example, I embarrassed myself because I felt like I was talking too much but pretty much couldn't shut up! I think I am much more sensitive to drugs than a lot of people, perhaps even more now that I've gone organic, etc. However, I certainly enjoy a mild boost. The onc. nurse I had today was surprised I was taking the anti-nausea stuff for five days – she said it was supposed to be three – but then I couldn't really remember what it was. (It's three days plus one morning on the fourth... the dosage seems to be the problem.)

I changed my chemo day to Monday instead of Friday which sadly means I won't have C anymore, but it works much better for my schedule, and also means if something goes very wrong in the days-after I can call the oncology nurses or my doctor rather than deal with a general advice nurse and go to the emergency room.

Again the cross-town quest to Misha's from chemo, very trippy. Misha was impressed that my oncologist didn't get miffed about the herbs... I see that I have an appt with Dr M on Sept 17, before my fifth chemo. I'm not sure if that's a mistake, as Dr S said he'd be away for two weeks, not five. If it's not a mistake, I may consider changing oncologists. I love Dr S but someone more consistent would be fab too. (Dr M will be my third backup doctor, and it always seems to be during some scan which is when I want the same doctor the most.)

Ever since I said in my talk that things are simpler, I don't feel guilty so much, etc., I notice myself feeling guilty more. How'd that happen? I wouldn't mind so much but dag blastit I do feel slightly guilty about it. Some plans are cooking up for next year – retreats, mostly in far away places, and a couple of them very long. And my Tarot reading yesterday had a lot of strong, positive cards suggesting healing, prosperity, travel, strength and meditation. So there. According to the potentially uber-reliable psychic-revelation.com, the 'final outcome card' in my reading has this meaning:

The 6 of Wands is a very positive omen. It can indicate that despite the challenges you are facing, you will overcome them and come out on top. This card also points toward literal or metaphorical movement; things are changing, in a positive way. In general, the 6 is about happiness and celebration. You are about to see some results for your hard work and efforts. Give yourself a break or treat yourself in some way. You have certainly earned it. Health: If you're worried about health, relax. Things are not as bad for you or the person that you're asking about as you fear. There is an underlying, spiritual strength that will sustain the health of the person you're asking about. Take heart.

August 8: **Tune-ups**

I've been feeling depressed the last couple of days, in the morning and at night. I seem to be complaining more in general. I gave those talks about how enlightening it all is, then, crash. It almost makes me

superstitious, like if you say everything's going to be OK, or that everything is OK, then the god/s will strike you down. Something about the low that follows the high, the confusion that follows the clarity. Reading [Sumedho's](#) book last night was helpful. As was meditating this morning. It occurred to me that I will have decisions to make if I still have cancer come November. I hope that I do not have to make those decisions.

Playing with various sleep aids. The Ativan pretty much doesn't work anymore so I'm going to try to stop taking it. I've gotten higher-dosage melatonin (10mg) and valerian (650mg), and marijuana (I used to call it 'pot' but now it's marijuana apparently). There is an edge of anxiety for me about addiction but that's just a part of all I'm working with. I feel completely different when I get enough sleep. Trying to type at my desk sometimes now rather than in bed. Posture is an issue – as the days and months pass, my shoulders move together in front, become concave. Will try sitting on the yoga ball too. It might not sound like a cancer issue but it is, because I've been hunched over this laptop for months in bed.

It's been sunny the last couple of days. I've walked by the ocean which I hardly ever do – with Viradhamma at Rockaway Beach (Pacifica), and Fort Funston with Lisa S. yesterday. My pedometer doesn't really work so haven't been logging the miles, but I can feel them. Walked up to Bernal Hill today with Elaine, Lisa Kee and Lauren. Feldenkrais this morning: all kinds of fleeting stabby achey feelings,

and occasional chills. Mostly deep in my pelvis or in my hip joints or knees. My feet are very numb today, and, strangely, my face.

I had a carne asada burrito for lunch. It's not very healthy, don't know what I was thinking. At least I seem to have gotten over the sugar craving for the moment. Someone brought over coconut bonbons and there were cookies from Hawaii. I love not feeling any conflict about things that are bad for me. Lisa Kee gave me an awesome foot massage this afternoon and I drifted off, bliss...

August 10: **Bodily changingness**

Substances that my body produces, liquid or solid, smell sour and toxic to me, and burn. It's strange that my body can be at once so familiar and so unfamiliar. I think: This is only the first half of it. What next? My legs are numb, and my face. My eyebrows fall out and lighten. Which isn't that big of a deal in itself. It's just that human beings tend to have eyebrows, so it makes me look like something else, unless I wear makeup, which then gets into and irritates my eyes (now that I think of it, probably because there are only a few eyelashes left to protect them). I didn't used to think of hair as protection.

Flickering sensations of pain: stabbing, sore joints. The tension collects in my heart, like a sentry that gets called every time I start to relax. Lying in bed at night, drifting off, then a small jolt in my chest. It causes me to pay attention to my heart and unify myself, when it is not dividing me. Sometimes with the changes in my body, I feel utterly alone. Still, at least I have more energy than I expected. No sores in

my mouth. I am vigilant about thoughts, usually predictions, that start to drag me down. I had a great walk and chat with Nancy, talking about how we deal with our bodies. Then Misha, and a reiki session with Tania. One of the things that came to her during the session was that I am not alone. She said she saw me surrounded by guardians, protectors...

From Ajahn Sumedho:

Notice how irritating it is just to be able to see, hear, taste, smell and touch. There's always something that isn't quite right... Just consider how sensitive we are in relation to words and thoughts. One can say things and upset everybody just through a certain tone of voice... We get a lot of guilt and remorse or self-aversion because of mistakes, failures or unskilful acts in the past that we remember...

Being born as a human being is a real challenge in terms of how to use this experience of birth, human experience, this sensitive state that we're living in... It can be so utterly depressing that we think it's better to kill ourselves. Or, as the Buddha encouraged us, we can wake up to it, learn from it, see it as an opportunity, as a challenge, as something to learn from. We can develop wisdom in terms of the conditions and the experiences that we have in this life – which are not guaranteed always to be the best. Many of us have had to experience all kinds of frustrations, disappointments, disillusionments and failures... Of course if we take that personally, we want to end it all very quickly. But if we put it in the context of knowing the world as the world, we can take anything. We have incredible abilities to learn from

even the most unfair and miserable, painful and nasty conditions. These are not obstructions to enlightenment; this issue is whether we use them to awaken or not.

August 11: **The influence of Seventh Day Adventists**

I think that taking melatonin and valerian at night make me feel depressed during the day. It is very hard to isolate factors with depression. I haven't taken anything for a few days, and the depression, which I felt strongly in my body, is gone. I have felt more awake during the day. I've also been walking for an hour a day. Anyway, the last few nights I've done without them.

There are at least two different approaches to illness and discomfort. One involves taking all the recommended drugs for each emerging symptom. I feel that diet, acupuncture and exercise are the primary reason that I have not been devastated by the chemotherapy (yet). Of course I can't be certain of that. My diet is not very strict these days. I try to eat a lot of veg and no sugar. Yesterday I had very spicy Thai food (tofu and veg) and it seemed all right.

My approach to pharmaceutical drug-taking is perhaps related to the fact that my mom grew up as a **Seventh Day Adventist**. She certainly resists prescription drugs. (For example, after 15 years of depression, which my sisters and I have found incredibly frustrating.) She says she will work it out herself. This is exactly what I say. Of course when I say I will work it out... I actually do. Yes? Maybe some people conceive of drugs as solving problems. I think of them as potentially solving

problems, and causing other problems. Chip off the old block. I think this saves me a lot of trouble (but maybe causes more, who knows).

Yesterday's pilates class was so fab. They had a party for August birthdays so I was crowned, etc. It was really fun. Also picked up my barium which I drink in advance of my scan this week. Went with Amy to see [David Shrigley's](#) exhibit at the [Yerba Buena](#). It was great.

I really ought not to think of myself as toxic. While I am being shot up with heavy metals among other things every three weeks, the toxins also weaken over the three weeks. And my body is 99.99% functional.

August 12: **Chemo dates**

I changed back to Fridays, because changing was causing other hassles. Plus I had a huge bruise on my hand after the last one. I thought it was worth sticking with C, who only works Weds-Friday.

A couple of days ago I wrote about how crap everything was. Most of that has since changed. No more burning pee, and I'm sleeping much better and not feeling depressed. My feet and face are still (say 15%) numb. Need to plan a week away toward the middle or end of a chemo cycle... sick of the city...

August 16: **Shaky trailer II**

Strangely, I found my scan today relaxing. You have to fast aside from this nasty (not as bad as Chinese medicinal herbs) barium drink. After you get shot up with radioactive sugar, you sit still, alone in a room for

half an hour. Oh yeah, and they check your fasting blood sugar. I think mine was something like 58. The trailer shakes a bit from the wind.

You have to lie completely still – very comfortable – on the scanning table, which moves you through the tube three times. The first two times are the CT AKA ‘Cat’ scan which provides the sort of map to go with the PET scan. The third time through, it spends four minutes on each area as it makes its way down your body.

Other than my shoulders hurting from having my arms above my head for so long, it was amazingly relaxing and meditative. Even though it’s in this weird trailer in what seems to be some kind of San Francisco wind corridor. I am sorry for the folks that work in that trailer. Though I’m sure they get paid well, and they only work in SF two days a week, the rest of the time they no doubt get to milder micro-climes.

There was a lady with a cane on the lift with me up to the trailer (apparently people injure themselves on the stairs). She said last time she was fine, but she had gotten really bad neuropathy (numb feet) so she couldn’t walk as well. She was sort of on the older side, don’t know how old. I thought, geez, I guess my neuropathy isn’t that bad...

After a ‘Castro Omelette’ breakfast at the [Squat and Gobble](#) in the Haight, we saw ‘[Total Recall](#)’ at [1000 Van Ness](#). I enjoyed it, and, it seems, anything post-apocalyptic. Plus Colin Farrell is terribly hunky. I haven’t been eating at home at all, it’s probably very bad. In fact... had popcorn at the theater with that super-fake butter which probably has that fake fat stuff reputed to give one diarrhea, and it did. (Thankfully

we had been early for the movie so I didn't miss anything.) Probably radioactive diarrhea, but that might be TMI? I am astonished by my own stamina. In the past if I would do this much I would start to feel like I was on the verge of a breakdown. Even going to a movie... But I feel fine.

August 18: **No scan results yet**

During Dawn's **KM (friendship)** ceremony at the Center, I looked over at some folks making offerings and I thought, Why on earth would I ever want to leave this place, these people?

The **pilates** class was great this morning. We walked to **Japantown** – about four blocks – and had lunch at **Izumiya**, then returned to go to the monthly support group, which was fab. Laura liked it. She suggested in the group that I say something about my mom. A couple of weeks ago I noticed that I was feeling crabby about her not calling me, which she has not done for many years, if ever. I got in touch with this longing for my mom to reach out to me, and I was getting more and more annoyed. I have been calling her once a week or so for many years. I didn't so much feel like talking about it in the group, I feel to some degree at peace with it. I need to be aware of this longing, a longing that will probably never be satisfied by interacting with my mother, or expecting her to 'act like a mom' because I have cancer. Many people shared their feelings about their mothers. The case worker suggested other ways of being nurtured, for example, by being in nature. I was interested in that because I usually think of nature-time in terms of being sick of the city. But perhaps there's more

to it than that. I do feel that I have many nurturing activities and people in my life. My sisters have been wonderful.

Preliminary scan results

The PET scan shows that two of the small lung tumors have about the same signal, but the other ones have shrunk to where they are not visible. The two with signal are not any larger. There are no new tumors. Overall, there has been response to chemotherapy. I'm not sure what 'with signal' means... I suppose it's to do with brightness on the scan? So, there are no new detected tumors anywhere, all the tumors in my lungs but two have disappeared, and the ones left are the same size they were. Keeping in mind that the scan can only detect things larger than around 1cm (I forget which scan shows the smaller stuff, is it the MRI?) the tumors could all be there still, but too small to detect. So worst case is still that they have only gotten smaller – either way, it's good news...

August 20: **Food**

Ideally I would have a veg-intensive whole grain vegan diet, perhaps with some sustainably-acquired fish. But I'm not doing that, at least not all the time. I'm also not sweating it. Eliminating very sweet foods is my main food project, and I feel that is very good for me, and the rest of it is good enough. However in spite of my exercise regime, which I am enjoying and benefitting from, my waist has grown about an inch lately. Too much eating out combined with too much eating no doubt! I just had a pot of veg with seaweed and miso. It felt great.

I was at UCSF hospital yesterday visiting a friend of Karunadakini's who is being treated for multiple myeloma. We had a great chat. I remember how fondly she spoke of "Dex" (short for dexamethasone, the steroid). Since then my whole mouth started hurting, mostly my tongue. I was wondering if I had caught something at the hospital. A friend asked if it could be thrush. After looking it up I feel that it probably is. The main dietary guideline is not to eat sugar... hmm. Going to try some home remedies like raw apple cider vinegar and probiotics. Will call the oncology nurses tomorrow and see what they say.

I sent a thank you to Dr K for the info about my scan and he replied: "You're welcome. Best wishes going forward. Dr M is a very good doctor as well." I started off with kind of a bad feeling about Dr M, after hearing that she didn't want to give me the scan results until meeting me, even though that would mean I had to wait a week for them. I hope I like her in person, as switching to her would be most simple. Among other things I need to ask if she's cool with the acupuncture and herbs, as I feel that is important for me.

Tong and I went for a walk up on Mount Davidson (with the big cross on it – you can see the hill but not the cross from Twin Peaks, weather permitting) but it was so muddy and cold we had to abort and go to the Randall museum. It's nice going about with a local who knows where stuff is. (Tong grew up in San Francisco.)

So much of how well or badly I think I am doing is really just a comparison to someone else – without even knowing I'm doing it – either to people who aren't sick, or sick people who seem worse off than I am. And yet, my health is always exactly what it is. I just wish I could sort out my point of view once and for all...

August 21: **49 today**

August 23: **People say I don't seem tired**

I was really tired for most of yesterday, and wrecked today (due to waking up at 3:30am). People continue to remark about how energetic I seem. Why is this? Could the steroids still be functioning, or is it the chemo, or the makeup?? Last night I asked Po, So I don't seem tired now? She said no. It's strange.

We asked Dr M today about dealing with insomnia. She said many chemo patients have it, but it is not from the steroids or chemotherapy, because neither of these are functioning much a couple of weeks after the infusion. The main assumption seems to be that it is stress/thinking, but I'm pretty clear that's not the cause for me. I feel like my body just wakes up for no reason, or for no mental reason. She suggested Benadryl, and I didn't ask her for anything else. I figure I can alternate between Ativan, marijuana, Benadryl, melatonin and valerian (not in that order) and that oughta cover it! And make sure I walk every day. It wasn't lost on me that the last couple of days sleeping was bad, and on those days I didn't do my 4k steps.

I had a nice mellow day yesterday – a great chapter meeting, a Thai massage, and a lovely little dinner that Karunadevi and Singhashri made. A bunch of folks pitched in and bought me a Kindle and a gift certificate from Amazon which I was exploring last night in the wee hours. Oh yeah, and Dayamudra and I saw Woody Allen! He is making a movie about a block away from here (20th and Lexington) and was standing outside chatting with someone. Various folks were standing on the corners trying to get a glimpse without being uncool. A lady said she saw Cate Blanchett the day before.

Paulette and I met with Dr M today. She was great! She's not as warm or funny as Dr S, but the info she gave was more useful, in the sense that I could understand it! She gave me a copy of the PET scan report and showed me images, and we talked for about 45 minutes. Before meeting Dr M, I mentioned to the medical assistant who weighs me and takes blood pressure etc. that people expect you to lose a lot of weight, have nausea, etc., when you're on chemotherapy. She said in so many words that this is an outdated view. The main problem used to be nausea, people couldn't eat, but there are now drugs to control nausea.

About the types of scans. The regular CT scan shows you the size of things. The PET scan shows glucose uptake/metabolic activity. Regarding size, the PET scans are harder to compare, because the next scan may hit a different part of the tumor. In clinical trials for change to be significant it has to be 25% or above. The reason I got a PET scan instead of a CT was to do with my pelvis more than my

lungs. For just my lungs, a diagnostic CT scan would have been better. (The CT scan that goes with the PET scan is a different kind – it's not diagnostic.) The MRI is for a detailed look at a specific area, often soft tissue.

The actual scan. There is one detectable nodule remaining in each lung. She also said she could see what was probably a little section of emphysema toward the bottom of one of my lungs. (I smoked cigarettes for a long time.) The long and short of it is, because the tumors started off so small and because of the nature of the particular scan I got, things aren't as definite as they sounded coming from Dr K. So, the therapy is probably working. It occurred to me again that there are other potential scenarios besides "I have/don't have cancer." At the end of the chemo, there could still be tumors – ones that aren't growing...

August 24: **Answer to my last question**

When I wear makeup and a wig, people are shocked at how healthy-looking and energetic I am. When I don't, not so much. Got an eyebrow tutorial from Dhivajri and Dawn today. But I'm not sure I want to fill in the eyebrows anymore. It makes people think I feel better than I do. Oh, and I found out that "Steam Punk" is a thing. I do not have my finger on the pulse of contemporary culture, apparently. It's not even pointing to the pulse.

I don't think I explained the diff. between a PET and CAT scan very well. Suffice it to say, one means domesticated animals in general, and

the other is a specific kind. Chemo tomorrow. I'll be done in six weeks. I suddenly thought I'd like to go to Mexico for the retreat that starts November 1. I wrote to Dr M asking her if that seems reasonable. Why the hell not? Because chemo could be really horrible later? What if it isn't? And maybe I should go to Sri Lanka with Kathy in December?

Finally, don't watch [Troll Hunter](#), the Norwegian The Blair Witch Project, but with red-eyed trolls. It is not as good as it sounds.

August 25: **Chemo IV with a dramatic interlude**

Chemo today with Padmatara. We didn't bring the whole house of food, movies, electronics and books. We were proud. Unlike what you might expect, I was kind of looking forward to it, or at least not dreading it, because I am now more than halfway done with chemo. There wasn't a private room available, so we ended up in the group room with just one other person who was asleep. At some point she left and Griz and his wife came in. He was a big guy, and referred to himself as "an old hippy". He was the friendliest patient I've come across, at first, but then his Benadryl kicked in and he didn't talk much. We watched a movie ([Son of the Bride](#), Argentina, it was pretty good).

C takes his time putting the needle in my hand. He wraps a heating pad around my forearm for around ten minutes, touches the vein and follows it with his finger a few times (not sure what he's doing there!), taps the vein. He's very slow and methodical which I really appreciate. Others just stick the needle in.

After PT went down to the cafe to get us an egg salad sandwich, Griz slumped over in his chair and, according to the alarmed nurse, who yelled “Help!”, stopped breathing. He had no pulse. Suddenly four more people appeared, including C and Dr M. Apologies to those of you who haven’t seen the show Nurse Jackie. I feel that I refer to it frequently. It is my main experience, if I may call it that, of hospitals. The difference this time was how calm the folks on the show are in an emergency. Of course their context is an emergency room. But Dr M seemed super stressed out. They don’t see this kind of thing very often in the infusion center.

I looked outside the door and Griz’s wife was standing there looking completely freaked out and sad. Our welled-up eyes met for a few long moments, then someone led her out of the room. They closed the curtain between Griz and I, so all I could see was the feet of the people closest to the curtain. Dr M said several times, “He’s not breathing, we need to get him on the floor” [for CPR]. At that point, there were only two diminutive women there and he was a huge guy, so there was no way they could move him. Then they couldn’t find the epinephrine! (Apparently there had been a drill the week before and someone hadn’t put it back.) Then they couldn’t find the mask that went with the oxygen bag. I’m sure their lawyers would be very unhappy that I am writing this. They did find the stuff very quickly!

Once the burly guys (paramedics and the fire department) showed up, they gave him epinephrine and he started breathing again. All these different voices kept saying, “What’s his name?” “Griz”. “Mr. Griz,

you're OK, do you know where you are?" Griz's nurse: "Miller, his last name is Miller." "Mr Miller, can you hear me?" He was still very groggy from Benadryl. It was all over in about 20 minutes and then the room was empty. Four different people (Dr M, another doctor, C, and someone else I can't remember) came up to me at various times after the crisis was over and asked if I was OK. I was alone on the other side of the curtain with tears welling up in my eyes. I felt calm, but I was listening to an enormous amount of stress, and Griz being pretty much dead for a while and the nurses searching for the things they needed to help him was kind of upsetting. Apparently they wouldn't let PT back in (there was no room for another person anyway). Someone then went out and told her what happened and let her back in.

Acupuncture was great. Misha's been putting a lot of needles in my feet, which sends all this energy pulsing through my feet, and I went into a very deep sleep.

August 26: **Pills and potions**

My life is so strange. Is everyone's life strange? Is there anyone who can say, with any degree of sincerity, "Yes, my life is perfectly normal"? Perhaps there are plenty of people who can say that, it's only that I've fallen in with the wrong crowd. Of course I've been abnormal for so long, normal looks rather suffocating. But I might be mincing things. Not sure if I'm talking about cancer anymore...

So many pills and potions today. Glutamine powder (for neuropathy) mixed with water 3x/day, ten or so herb pills taken not with

food 3x/day, dex and zofran in the morning, and zofran in the evening. The last two have to be taken with food or they will give you a stomach ache, which also happens if I forget to take them. Then the more standard: D3, calcium, fish oil, B Complex. Senna for constipation caused by deximethasone, plus whatever sleep aid I am taking that night. Ginger tea for fatigue and digestion. Green tea. I'm also dosing out on probiotics, ideally half an hour before eating, which makes me feel a lot better, less weird. No added sugar except a little stevia, no processed food, alcohol, caffeine (except green tea)... Sometimes the only word I can think of to describe how I feel is 'weird'. Am I too spaced out to come up with something more articulate? Or perhaps there just isn't a reference point.

There's also the burning mugwort (not to be confused with Hogwarts) stick, yoga ball exercises, dealing with the tightness in my hips and the hunchedness of my shoulders, keeping my feet warm, walking at least an hour a day. Support groups, medical appointment juggling, acupuncture, pilates, feldenkrais, the yoga I'm not doing. Keeping track of all the pills and supplies, keeping them stocked. And things to wear on my head: wigs, wig caps, scarves, scarf-tying techniques... Anyway. My pill and potion regimen is most intensive the first couple of days after chemo. I am both tired and not-tired at the same time. Lethargy married to mania. Lethargy/fatigue mostly stays on the inside, mania comes out. The routine changes after four days, ten days, and fifteen days. I have it all written up on a complicated spreadsheet.

I smoked some pot last night. I noticed I felt kind of guilty about it, but it helps me sleep, though it also makes me feel even weirder. It makes me feel like I am occupying two worlds: the stoned world I lived in when I was a teenager within the shell of my current 49-year-old world, coping in different ways with having cancer each moment of my life.

A note from Dr M

I think it would be great for you to get away and have some nice vacations. You have chosen some interesting sites. Based on seeing you once and the status of your cancer, I think the trips sound very feasible and that you should go ahead and book the trips. If for medical reasons you are unable to go/fly, we can write a letter for you (as well as any companion) that will typically allow you to get your money back for the flights. Hotels, cruises and other arrangements, though, are harder and might justify purchasing some travel insurance. Have fun planning

P.S. Again, I am sorry you had to be present for the excitement associated with the treatment reaction. Just FYI: The gentleman is doing very well – left the ER after a few hours and called on Monday stating he felt fine.

August 29: **“A complete response to treatment”**

I had another gyn exam with Dr K today. I think my last exam was in June, when he said there was some scar tissue (and the exam was painful). This time, the exam was not painful and he said there is no

scar tissue and I have had “a complete response” to treatment. In other words, there is no residual cancer, and it is unlikely to recur there.

So now there’s just my lungs.

I’m going to drive up to Seattle with Tong and fly back Thursday.

*

Me and other people: Love

4 February 2009

There is a path from me to you that I am constantly looking for, so I try to keep clear and still as water does with the moon.

Rumi

My relationship of the last seven years ended in October, and my life has changed drastically since then. Not how it looks or operates on the outside so much, but how it feels, how it looks, how it tastes. The main area that has changed is my experience of myself in relation to other people. Of course I felt sad at the ending of the relationship. But I think in general I feel more loving and open. More vulnerable even. It feels really good. I feel a lot of love for people. I wish it were more; I wish it were all the time. (Being loving all the time toward everyone including myself is the essence of my interest in Buddhist practice.)

But with men, it's different now... I experience them as men. Before they were people first, and men somewhere in the second or third degree of observation. Now, through the emergence of some dark and dusky neediness, they're men, and in an entirely non-willed kind of way, I somehow want their love. The only requirement is that the man is single. I do not even have to be attracted to him, though the dynamic will be very subtle if I'm not. So this is the new and most salient expression of thirst, in the Buddhist sense, in my life.

A further irony is that along with this thirst is the conviction – yes I think I can call it a conviction – that the nature of sexual relationships, at least for me, is dukkha, suffering. This means that even if I feel very happy, this way of relating to men, to whatever degree it is happening, gives a corresponding sense that I am embarking upon a path of pain. So there's this slight movement inside me toward the thing I harbor the deepest suspicion of. I can do nothing about all the ironies really but watch and be amused.

For years I've sometimes thought about taking the anagarika precept. But if I did, would it be simply because I have such ultimately incompetent taste in men and figure, what is the point of carrying on? (Not that all my partners haven't been lovely, just that I could not be happy with them for long.) Obviously I will need to resolve this question to some degree, regardless of whether or not I decide to become an [anagarika](#).

I am determined not to keep doing the same thing, falling into a situation not knowing what it is, really, or who it is with, guided by unknown [samskaric](#) trash. A book I read recently ('[The Brain that Changes Itself](#)') said research has revealed that 'falling in love' and cocaine affect the brain in very similar ways, and in certain ways the ending of love is neurally indistinguishable from drug withdrawal. So I know all this, and I think I'm going to be sensible about it all, but then the hormones or whatever they are (endorphins?) kick in, and I wake up at some point having dug another hole for myself that I'm trying to claw my way out of. The determination not to do this again seems

stronger now than it has in the past. But one never knows. In the face of some things I am quite helpless.

All of which might sound bleak. I am enjoying these realizations. I know that pain cannot be avoided, and that much of the time our attempts to avoid pain simply cause more of it. I am just noticing what's going on, which is to a large degree about my own tangled-upness in regards to sexual relationships, and noticing my subtle (I hope) neediness around some men.

I am noticing how much notions of self-view and self-worth are tied up with sexual relationships. I am noticing that these aren't things I'm deciding to do. Seems more like they are being done on me. They are just happening, and I am trying to be aware and loving as they twirl around and inside me.

September 25: Another example of what I don't look like.



September 2012: The reason you have to face death

September 1: **Hairless, by Jo Shapcott**

Can the bald lie? The nature of the skin says not:

it's newborn-pale, erection-tender stuff,

every thought visible, – pure knowledge,

mind in action – shining through the skull.

I saw one, a woman, hairless absolute, cleaning.

She mopped the green floor, dusted bookshelves,

all cloth and concentration, Queen of the moon.

You can tell, with the bald, that the air

speaks to them differently, touches their heads

with exquisite expression. As she danced

her laundry dance with the motes, everything

she ever knew skittered under her scalp.

It was clear just from the texture of her head,

she was about to raise her arms to the sky;

I covered my ears as she prepared to sing, roar,

to let the big win resonate in the little room.

September 2: **The reason you have to face death**

The reason you have to face death is that the only alternative is to live locked down by fear. If you have cancer and you're fighting it, and thinking, "I just can't die. I'm not going to die. Dying is not an option, NO!" then you have to live in fear of something you cannot control. You have to hide. You have to pretend that what is real is unreal. You have to act like you have a choice, that choosing life is an absolute choice. It's true that we can choose life, but that choice is simply an openness.

Cancer is not only part of life, cancer is its own life. A friend wrote to me recently: I'm taking a therapeutic yoga training and am hearing all sorts of wonderful and miraculous healing stories, in addition to practicing the tools. I heard one today that reminded me of you when you talked about 'not wanting to fight your body'. An older woman with cancer had a little talk with her cancer on a regular basis. She told it that she had no problem coexisting with it, but it was simply too big, and if it took over and she died, then it would die too, and that wouldn't help anyone. So she regularly asked it to shrink, and you know the punch line! She's alive and well years later, with no chemo, just regular check ups to see that tumors are staying very small! I like this approach. (It's also true that her talks with cancer did not necessarily cause her recovery.)

Life and death can't be denied or affirmed separately. So if life is OK, death is OK... Not for someone else, for oneself. Of course I'm glad my friends and family do not want me to die! But none of us has a

choice either. It's life's choice. We can influence life. It's all about the difference between control and influence. I constantly mistake one for the other. And trace it all, or much of it, back to not wanting to die. Social death. Losing everything, wanting to hold on. Everything we want: love, power, agency, prestige, talent, money, stability or excitement. Symbols we use to control life...

Why shouldn't everything that is horrible also be interesting? Across the street from Misha's, I saw two little mice lying on their sides on a piece of paper on the pavement. How'd they get on the paper? (The piece of paper with the mice said 'Catchmaster' on it. I looked it up and it said, "Manufacturers of adhesive pest control products".) One of them was dead, the other was on the way. I thought about moving this paper with these poor mice on it so they could die or be dead somewhere better than the curb, but it seemed that might disturb them more so I left them. So I thought, in spite of what I wrote above, death is awful. At least from the outside. I suppose from the point of view of the dead, being covered with blood or shit or lying on a curb is of no concern. The time for concern about dignity or appearance is over.

Because of the sores in his mouth,
the great poet struggles with a dumpling.
His work has enlarged the world
but the world is about to stop including him.
He is the tower the world runs out of.

Dean Young, from "Elegy on Toy Piano"

September 4: **Seattle (chemo day 12 of 21)**

I was super-tired yesterday, which landed within the five days of my 'immunity nadir'. Also could be because of a longer-than-usual walk yesterday. On the positive side, I am able to sleep a bit more. My friend Oscar has the most comfy guest futon imaginable. What's his secret? I've gotten together with a few people here... it's been really sunny and mild, perfect weather. Oscar and Debbie have a case of the most delightfully ripe peaches.

Melissa told me about some studies done in Japan on 'Forest bathing': men who took two-hour walks in a forest had a 50-percent spike in levels of natural killer cells. Another study found an increase in white blood cells that lasted a week in women exposed to phytoncides in forest air. So there is more motivation, other than how I feel, to get out of the city fairly often.

September 7: **Needles in my face (yay!)**

Got back from Seattle yesterday and went straight to acupuncture. I've got a numb face which has gotten small sores on it as well, only on the left side. Misha put lots of needles in my face and in my feet, one of which, when she put it in, made me practically jump off the table. Some of them are painful when she puts them in but it's the kind of pain I don't mind. She said she hoped the face thing wasn't shingles (herpes zoster), which people can get from chemotherapy.

I'm wondering now if it might be simply from getting too much sun in Seattle. It was sunny and hot and I went for many long walks.

I was lying there with all the needles in me, thinking about how I might describe how it feels. It's not easy because there isn't anything I can think of to compare it to. It's energy, like there's something more alive about one's body. But it's not energetic, it doesn't make you want to do something, not like energy you get from, say, caffeine, or even meditation. It's subtle but somehow intense. I'm sure it doesn't look wonderful from the outside, though it certainly feels wonderful. It gives me a completely different, joyful experience of my body. Today, very tired. Went back to bed instead of pilates, which I've missed for the last two weeks, and will miss next week because I'll be at chemo. The guilt was subtle. I felt great when I got up at noon.

When I was in Seattle, I noticed that people tend to share their health problems with me. My friend (who is younger than me) said he's worried about what he's going to be able to remember, and how his eyesight has gotten very bad. And as people age they spend more and more time dealing with health issues, many of the same ones I have – bowel issues, lady parts, insomnia, cancer, fatigue, memory loss, hair loss, and more... I did read about a study on exercise in middle age and how it can help (other people anyway!) The results show, in essence, that being physically fit “compresses the time” that someone is likely to spend being debilitated during old age, leaving the earlier post-retirement years free of serious illness and, at least

potentially, imbued with a finer quality of life. By 'exercise' it doesn't mean doing a marathon, but simply walking for half an hour a day.

September 9: **My disease sounds bad**

"Stage 4b Cancer of the Vagina". But there have been positive developments since the initial diagnosis. Currently I have metastatic ('rapid transit') cancer in my lungs, plus insomnia, numb feet, numb left side of face, slightly low immunity/white blood cell count (last time we looked), alternating constipation ('constriction of body tissues') with diarrhea ('flow through'), and alopecia ('fox mange'). I also have the vitality for a fair amount of perambulation, dialoguing with fidus Achates, disease and symptom management, and inscribing these notifications.

Two anecdotes:

At my last exam with Dr K, he referred to me, again, as 'young'. I asked, "So what exactly makes me young compared to your other patients, that I am not 70?" He said, "No, that you're not 85."

Someone with stomach pains visits her doctor, who asks if anxiety might be the cause. The patient says, "Well, I am afraid of dying of cancer." The doctor replies, "We're all going to die of cancer."

September 10: **Countdown**

My last chemotherapy session, for this round anyway, is 24 days from today. (Penultimate is this Friday.) Had a fab time giving a talk at the Gay Buddhist Fellowship on Sunday. What lovely guys. It's one thing

to give a talk that people find useful, or moving or whatever. At this talk, I felt people's hearts open, how delightful that was.

In general, I'm feeling hella bored with cancer. Ten months!

September 11: **A toothless dream?**

On the way home from giving \$140 to the fine folks at Whole Foods, part of one of my back teeth fell out, painlessly. I didn't even know it until I felt the gap in the back of my mouth. According to a random internet tooth map, it's my upper left second molar, or you may simply call it "15", kind of like [Agent 99 on Get Smart](#). I'll talk to Dr M about it tomorrow. I seem to remember that there is some problem with getting dental work while you're on chemotherapy. Some of my fillings are ancient, so it's not necessarily related to cancer/chemotherapy, unless it's somehow related to the 'weirdly numb left side of my face' syndrome. Or maybe it's part of one of those dreams in which all my teeth fall out. Perhaps I'll wake up some time soon, that'd be awesome.

'Cuz in this life/possible dream I've been feeling a lot of fatigue and craving, and ate four – or was it six? – very dreamy [Dilettante dark ganache chocolates](#). Yesterday half a bar of [Seattle Chocolates Dark Chocolate Coconut Macaroon Truffle with Sea Salt](#). Mmm. Having brought them back from Seattle, was planning on giving them away...

September 12: **The doc's point of view**

Dr M is my main oncologist now. Manner-wise, she's uptight compared to Dr S. But I guess being entertaining probably isn't the

main thing one should look for in a doctor. In any case Padmatara noted that I have improved whatever the patient side of bedside manner is. Well. She didn't say improved. She said "more assertive and clear," I think.

I have been very tired since we got back and have done the thing that a person with sleep issues is advised not to do (in fact was advised today not to do): lie in bed for... six hours. In the past I would have fallen asleep and then gotten up. But because my sleeping habits – or are they capacities? – have drastically changed, I can lie in bed for a long time without falling asleep. Still, resting is good.

One is supposed to reserve one's bed for sleeping (or sex). Instead of both, I plugged my new JLab speaker into my laptop and watched the end of episode 2 of [Battlestar Galactica](#). I seem to be accumulating a lot of gadgets. I read half of *This is getting old*, a collection of sweet essays. I listened to a talk by [Peter Coyote](#), who lives in San Francisco and is a Zen priest. I ate chili with kale, potatoes and goat's cheese.

I have a dentist's appointment tomorrow at 5:30. Dr M assured me that going to a dentist in such a case is good. It's just that you don't necessarily want to schedule your regular checkups during chemo. It's an issue of exposing yourself to your own germs. (She says that's usually where the germs come from, not other people.)

Here are a few other things I talked to Dr M about: Neuropathy – even though mine's getting worse, apparently it isn't that bad! The danger signs are pain and losing balance. She said that the worse it is, the

more likely it is to continue after chemo ends, in which case I am screwed. My feet don't hurt unless Misha sticks a needle in them. I just need to be careful of hurrying down stairs. But I do sort of worry about the neuropathy. My one worry, pretty much, is being disabled after treatment. (I suspect fairly regularly that I am repeating myself, but if your memory isn't better than mine, then we're golden.)

Before switching to Dr M as my primary oncologist, I wanted to talk to her about complementary medicine and make sure she isn't going to protest. When I first brought it up she was somewhat skeptical. She mentioned being blamed by patients for problems caused by herbs. After I told her that Misha participates in studies at UCSF and checks the interactions very carefully, she seemed to relax, and said if it's worked for me for this long it's probably fine.

I had thought that doctors being skeptical about herbs, etc., was simply some kind of prejudice they pick up in medical school, but today it seemed to be more about her practical experience of people taking herbs adding work for her (to check interactions), and about causing bad interactions with the chemotherapy which the prescriber perhaps doesn't understand. Misha is not a typical acupuncturist. I also told her that Misha is convinced that the reason my blood counts have been so high is due to an herbal blend called Marrow Plus, an idea she seemed receptive to.

September 15: **Optimism on steroids**

I got a 'resin composite' temporary filling yesterday – a layer of mild acid to help with bonding, a layer of bonding, and a slightly colored top layer, with no anesthetic. It hurt a bit, that searing, nervy coldness you can feel only in your teeth at the dentist, and it is only at the dentist that you mustn't move any part of the inside of your mouth when you feel it. I think when he was doing the acid, he told me not to move my tongue, which was difficult. Apparently my tongue had been flying all over the place. It's so incredibly awkward having someone plumb the depths of your mouth – with all that weird equipment, weird sounds, smells and pain. Anyway the whole deal lasted only thirty minutes, and now the upper left side of my mouth feels way less sensitive than it has for a long time. I will need to get a crown eventually, but this filling will last years. My dentist is a very sweet man. He seems upset by my cancer, and to know nothing about it.

This morning, my alarm clock did not make any noise, so I randomly woke up at 8:35, ten minutes before I was supposed to leave to get to chemo. It takes me more than ten minutes just to rally the various aspects of pretend-hair I have going these days. I don't like being late for appointments.

I'm in the infusion center on my own today. Julie is sick and I decided to use the hours here on my own so I could catch up on various things I need to write. I'm in the group room, mostly buried in my laptop or a magazine. The other patients are primarily older men, except one woman, ah, she and her friend just went to the private room. That's one advantage of having someone with me! The woman

who replaced them mentioned that her 50th birthday is coming up, so it's not all oldsters, the definition of oldsters being, of course, older than my current age. She has multiple myeloma in her mouth/teeth, for which she got radiation, horrible!

Yesterday I had a Skype call with Pasadini, who had been diagnosed with follicular thyroid cancer on that very day. She's a good friend anyway, but there's something about talking to someone with cancer that is additionally satisfying. She hasn't talked to an oncologist yet; possibly she will only need surgery to have the lump removed... I hope so. It seems to me that the cancer 'meme' is far heavier than the actual experience. But people (older people, unhealthier people?) often have more trouble than I. I think that the severity of side effects is always going to be relative, to some degree, to how bad you imagine it to be. I thought I was going to be deathly ill. For several weeks I was in a lot of pain from having my entire pelvis burnt outside and in, and I have many side effects, but so far, especially this round, nothing too severe. In this country the biggest issue is money/medical insurance. If you don't have it, or you have shitty insurance, it's financial – if no other kind of – ruin.

The nurse gave me some more detail about white blood cell counts. The five different kinds of white blood cells correspond to levels of maturity. Neutrophils are the most immature, so they bode well for the future! But my overall white blood cell counts dropped a lot in three weeks. If the “absolute white blood cell count,” calculated by an algorithm using total white cell count and neutrophils, is less than 1.5,

they usually postpone chemotherapy. Mine is 1.4, dang (but of course Dr M said I could go ahead, which is why I am here, yay!) So I'll be giving myself the daily shots (Nupogen) this time, the bone-crusher (hopefully not), to help with blood counts. I might have to do it after my last chemo also. Last round, I kept wanting the treatment to be postponed. This time, having reached my potentially penultimate chemotherapy session, I will do whatever I need to do to make sure it happens, so I get to finish and go to Mexico for three weeks!

I smoked some weed tonight, which made me ravenously hungry and not sleepy. So I'm going to lay off the stuff for a while, that is not what I need. Kathy warned me not to bring marijuana to Singapore. Apparently whenever they come across a medical marijuana card, they set it on fire. Putting together my upgraded bed, I was reflecting on my Skype conversation with Kathy earlier tonight. I spoke with great ardor about this round of treatment, and my optimism about outcomes. And about how odd it feels to be optimistic, either because of my formerly nihilistic tendencies, or perhaps from having experienced as an American too much forced optimism. I feel very optimistic about Pasadini, too. And all this optimism is on steroids right now. I wonder of all the people in the US who get whatever kind of cancer, how many of them die within five years? A great many people recover from cancer, [Lance Armstrong](#) isn't the only one...

September 16: **More on the subject of "looking sick"**

Yesterday I went for a forest bath in the [Botanical Gardens](#) with Vicky, who is a teacher over at Zen Center and an [Iyengar yoga](#) instructor

(and probably other things!) At lunch she asked about wearing the wig. I remember saying that I don't want to walk around with a head screaming "Cancer patient". However sick I am, I do not want to look sick before opinionated, even concerned, strangers. (Although not looking sick when you are also has some disadvantages. For example, someone seeming to be jealous that you look perfectly healthy but somehow get to spend a lot of time going to acupuncture or Feldenkrais classes, etc.) She – having been involved in some bad accidents and dealing with a lot of ongoing trouble – agreed that she doesn't want to look sick either. She also mentioned that when she had shaved her head – part of Zen tradition – she noticed lots of people on the street staring with a strangely concerned and shocked look, no doubt thinking she had cancer. My wigged head felt affirmed.

Later Mary and I went to the [Rigoletto](#) simulcast at [AT&T Park](#) – it was great, but hella cold – and I mentioned the conversation with Vicky. Mary, who also has some health issues, agreed that she doesn't want to look sick either (knowing, too, the downside of being sick but not looking sick...)

This morning I got ads for hair loss products on two different web pages. I haven't googled anything to do with hair for quite a while, but I have been talking about it... Has to be a coincidence, right?

September 17: **Sleep 'n' drugs**

Dr M gave me some sleeping tips at our meeting last week, most of which I am already doing: exercise early in the day, caffeine early in the

day, drink warm milk, go to bed at same time every day, don't take naps, don't do work or watch TV, etc., in bed (definitely guilty of this but I have since moved my computer to the desk...)

I wonder if any of these things really apply to me? It's not that I'm not sleepy, I lie in bed very physically and mentally tired, get to the point just after which I would ordinarily be asleep, but my body either stays in the 'almost asleep' state or, more often, slides up and out of it again. If I'm tired during the day, I can lie down for hours without falling asleep. All these things are entirely new. According to Dr M, there's nothing about chemotherapy itself that causes insomnia, other than mental stress. I don't feel stressed (well, other than the last couple of days!) Yet during my first round of treatment in Jan/Feb, I slept a lot, especially toward the end, ten or twelve or more hours. And before this ordeal began, I was a champion sleeper. I don't even enjoy it anymore, possibly because it's usually drug-induced or not very deep. It's kind of like a job now.

I asked her for a prescription to Trazodone, recommended to me by two people as a sleep aid. I have since looked it up and seen that it is an anti-depressant that makes you sleepy. It's supposed to be non-habit forming, but Dr M seemed dubious about that. I don't feel like I'm much of a risk for addiction, but I'd prefer take something not narcotic/less likely to affect me the next day. On the other hand, it seems that I feel sleepy the day after I take the Traz. Perhaps I'll try to take half? Even melatonin (10mg, kind of a big dose) makes me feel depressed the next day, so I have stopped taking it.

Smoking marijuana has allowed me to go to sleep a few times. Dr M said, as I suspected she would, that smoking a small amount isn't going to affect the tumors in my lungs. She also said most of her patients use it for nausea, and they eat it. But I'd rather smoke it, and I don't want to eat brownies or whatever it is they put it in. Last Tuesday night, no pills, just a couple of puffs of mostly ashes, and then I fell asleep. But last time, after chemo, it did not make me at all sleepy, only ravenously hungry, which is why I haven't liked it, recreationally speaking, for decades! Of course the lethargy was also part of what I didn't like, but now I'd like only that part please.

Some background

Californians first approved the use of medical marijuana for the seriously ill in 1996. While marijuana remains illegal under federal law and some cities and law enforcement officials take the same view, storefront collectives were approved by the state Legislature in 2003 and operate under guidelines published by then-Attorney General Jerry Brown in 2008.

September 18: **Swimming in a pharmaceutical soup**

I gave myself my first shot yesterday. It wasn't hard to do, nor was it painful, but afterwards I felt like a bona fide, dazed cancer patient. Much improved after a hour's schlep up the hill with Padmatara. Total today: 11,400 steps. Now I get to lie in bed! Two days after I fixed up my bed so I stop being too hot, I was freezing cold almost no matter how many piles and layers of blankets I had. I bought a heating pad today to wrap around my numb feet.

I'm seriously considering not saying 'dude' anymore. On a crowded tram the other day I listened to a couple of young white women talking next to me, sounding, frankly, like idiots. Which is to say, they sounded quite a lot like me. So many superlatives and hyperboles, as if every feeling were the most important thing ever to happen. I used to embrace my righteous roots in Southern California idiom, but I just don't know anymore. It's like the time in the 7th grade when I started hanging a silver heart from one of my hoop earrings, and within months around Davis Middle School there was nary an earring without a heart dangling from it. Admittedly, these kind of trend-setting events have been infrequent in my life. Still, fifty percent of Wichita bankers are reported to have accents with origins on surfboards in Newport Beach. Thanks, Hollywood. But wait a second. Does my way of speaking derive entirely from Southern California, circa 1976? Might I myself have parroted some of it from [The Simpsons](#) and [South Park](#)? Still, maybe I'll see if it's possible to stop exaggerating and saying like, just one day at a time...

I'm not saying any of this has anything to do with cancer, and I'm not saying it doesn't. However, as even [John Muir](#) would have to agree, when we try to pick out anything by itself, we find it hitched to everything else in the universe.

And from [Susan Moon](#): "I think I've earned the right to break free from the imprisonment of sequential thinking."

September 19: **Subtle stress**

Wonderful sleep last night, though presumably the Traz is the reason for the astonishingly vivid, deeply realistic dream, or sequence of dreams. I remember feeling the exact cancer-related physical sensations I have in waking life. I kept waking up or becoming conscious in a new place, not remembering how I got there or what I had done. I had the thought at some point that I need to just go with it, that if all this crazy shit was going to happen, there was no point in fighting it. And things got easier. But I would kind of phase in and out of knowing that, and wake up in another place. Finally, I went into a Tibetan gift shop and asked the lady behind the counter if she'd be willing to help me if she happened to see me wandering around. At first she was skeptical, but then she agreed. I woke up disoriented, still thinking it had all happened (perhaps it had), but that this time I had managed to land in my bed. Still, I had that rare and wonderful feeling of having slept deeply.

Dawn practiced some craniosacral on me last night. So relaxing, and so much energy, too – vibration and release. At the end she said something like that the left side of my body seemed less alive. This felt true to me, too. I should clarify that the night of having slept deeply is more likely due to the craniosacral than the Trazodone, which doesn't work that reliably and, so far, makes me groggy the next day.

Padmatara came with me to Feldenkrais this morning and loved it. She said it was like going on retreat, so true. It is a wonderful, subtly transformative mindfulness practice, and I keenly feel the change, almost a softening of the nerves, by the end of the class. At the

beginning of the class I am aware of the subtle stress – this sort of jerkiness – in my body that smooths out by the end. The focus of the lesson was the softening of the eyes. It was fantastic. Then Lands End was exquisite, though I have to force myself to walk. I think the shots are giving me motion sickness (just from walking) and if I might add, turning my bowels to rock. I could take yet more drugs to counteract the drugs counteracting the drugs. So I came home and had leftovers for dinner and wrote in bed for many hours with my new heating pad on my feet. Watched ‘[Sweet Home Alabama](#)’, which made me tear up a few times even though, or because, it was so sentimental.

September 21: **Only three things**

I’ve decided I need to pare down my calendar to three things per day. For example, yesterday: Skype call with Pasadini, acupuncture, and dinner at [Foreign Cinema](#) with Danamaya and Julie. Today: pilates class, support group, and Skype call with Kathy.

I skipped the pilates today though and stayed in bed watching a movie, ‘[Walking Tall](#)’, recommended in a nonfiction book I am reading. I must agree with the incarcerated ladies in my book that Wayne Johnson, who hails from Hayward, is super fine. It was a good movie. My barometer for that is based on whether, or how many times, during the movie, I think, That’s dumb! or That doesn’t work, or What a shitty actor. It’s pretty much a violent vigilante movie about a guy who always does the right thing. (Apparently the ladies in the West Virginia prison didn’t care for [Lost in Translation](#).)

The support group was good. Not as many regulars. One lady doesn't have a stomach. (I almost said, Wow, free gastric bypass surgery but decided against it.) A new guy with slurred speech from a tumor on his tongue told us about trying to walk to the bathroom and passing out in his apartment. Two women – including one with a tracheotomy – had been clear of cancer for six years, and yet they attend this group every time I've been there. And I heard that there is a shot you can take for blood counts which you do only once (as opposed to seven times like the one I am doing!) It occurs to me that their blood counts might have needed less of a boost because of the kind of chemo they're doing? Anyway if it's suggested I do the daily shots again after the next chemo, I'll ask about it.

September 23: **Grease head**

All right. I have identified that my trouble is not coming from the shots I am giving myself. It's the Trazodone that was making me more lethargic, in my guts and in the rest of my body, and depressed every day. I wish I had gotten Ambien. At this point I don't care about the potential addiction, and with other drugs I have taken, it is not an issue. Traz is crap. I didn't take it last night and already I feel so much better. Constipation is a potential side effect of both Trazodone and Neupogen (the shots). That's gotten a lot better, too. Today I developed a reddish bump on my forearm above my wrist. Folks thought it was probably a spider bite. I'm going to take some Benedryl tonight, see if that helps.

I used to have oily hair. Now I have an oily head. Makes sense, doesn't it? My head has a kind of muskiness that transfers to my head covers unless I take precautions. I seem to favor one-step head covers for around-the-house needs these days, like the one that Nora sent me from Hawaii, and a few buffs that Dhammagita sent. I'm using the pretty scarves, too, but mostly not wrapping them around my head. My face is still a bit numb, that hasn't changed.

September 25: **An issue of bilateral symmetry**

Slept last night without aid, after reading much of the amazing graphic memoir called Fun Home (ironic), by Alison Bechdel. Her angry, sad father appeared in my dreams... And I woke up feeling sad. Sad that I am still dealing with cancer, and isolated in my body in dealing with it. There is plenty to be happy about, too, but the feelings this morning were bittersweet. Fall in San Francisco. You don't see it so much, but you very much feel it in your body, and everyone says they're tired. I'm not feeling so much tired as tired of. I wonder if part of the reason for my apparently eternal equanimity and/or optimism could be Prozac. I take a very small amount, and every other day, but still. (Actually these days I'm mostly forgetting to take it. Hence the sadness?)

I still have a lump just above (anterior to) my wrist. The swelling's gone down and it hurts less, not sure I can be bothered to get it looked at. Daily eyebrow creation is getting more challenging, so little real hair left to guide the pencil. One sometimes ends up above the other and I have to erase and start over again. Drawing symmetrical things has always been challenging for me.

September 27: **Round two sloooooowly draws to a close**

Apparently it's common for the end of treatment, and near the end of treatment, to be hardest. Amen. Beneath everything, beneath whatever I am doing, whatever I am saying, I am waiting, waiting to find out if I still have cancer. It's always there, the question, the waiting. These days they're rubbing together like a cricket's wings.

For the last couple of days I've been feeling pretty healthy. Bowels seem to be embracing the Middle Way between the extremes of nihilism and eternalism. My feet occasionally feel like they have been replaced by padded 2x4s. They are very alien, but they don't hurt, so far. I walked to Misha's today (takes about 45 minutes at what is for me a fairly brisk pace). The first while after chemo #5, probably because of various other drugs, maybe because my blood counts were low too, in addition to the specific issues I was having, I felt really weird, and I don't any more.

In terms of media, last night I enjoyed *The Reader* with Kate Winslet and a cute German kid, and reading *Cancer Has Made Me A Shallower Person*, again. It's very good. I'm sorry its author and illustrator, Miriam Engelberg, did not survive. Before she died, did she think, Will people read my book some time in the future and be sad that I'm dead? I wonder.

September 28: **Personals ad #2**

My friend Mike and I got together tonight and talked for many hours, tried on wigs, and went to Thai House for dinner. OK, and smoked a

small amount of strictly medically necessary weed. I've known him for around twelve years and it was a first. We were talking about relationships (to the extent that we could focus on one topic). Based on some things I apparently said, he put together the following excellent start to a personals ad for me:

I've never been in a relationship that was satisfying.

I can't think of anything positive about any of them.

I mostly never see anyone I'm attracted to, except sometimes in movies.

I thought for effect it would be good to add:

I have terminal cancer.

For some reason, it isn't nearly as funny writing this as it was saying it. Maybe you could smoke a J and read it again?

We talked some about our teenage years, which were remarkably similar, happening as they did at opposite ends of the country (Southern Cal. and Maine). It seemed that on the subject of my past relationships, I often don't have anything positive to say. It's not that I feel I've been abused or misled, mostly just that I've been an idiot. It sounds harsh. I can't justify feeling this way; it's what has happened, though. There are things about relationships that I miss sometimes. Anyway, even though this is my True Confessions Blog of Cancer, I find this topic kind of embarrassing, so never mind.

P.S. Got a massage yesterday up the street at Relax Feet. Getting a massage these days can be slightly stressful, my body being unpredictable, and I don't tell them about the cancer because then I get a shitty massage. Anyway the massage was great, except the part where the masseur rubbed off my eyebrows.

*

Embracing Suffering

29 July 2011

The human body at peace with itself
is more precious than the rarest gem.

So says the great 14th-century sage Tsong Khapa. But even if you know this, even if you know this with a large part of your heart, life is still difficult, at minimum, sometimes. It seems that we often don't want to be at peace, or we can't, either because our inside world or the outside world will not let us. However, if you look at the 'outside obstacles' for long enough, you might find internal ones behind them.

So one problem is being tricked into thinking a problem is coming from outside. For example, my partner drives me bonkers. (Or dating. Or not dating.) Or something like what happened recently, a waiter spilled (a lot of) salad dressing on my leg. It's another kind of suffering to know that the primary cause cannot be outside, to see that and to lack the drive or discipline to act on that knowledge.

Sometimes knowledge is unable to serve its function, it just tortures you, you cannot align with it, it cannot link with the core of your life, your soul says no. Then knowledge stays on the surface, making some experiences seem right and others wrong. It makes you want to do something with your life, improve things, be busy, tackle problems, gain insight. Or feel like you should. We build a castle of our desires – even spiritual ones – then lock ourselves inside it.

So there's the suffering of, say, my 78 year old mom, who is angry that her brain is shutting down. There's the suffering of witnessing seeing someone you love deny reality. There's the suffering of having the life that you want but being somehow or at least occasionally unable to move within it. There's the suffering of thinking there's something wrong. There's the suffering of looking around and feeling that you should be happy, or happier. The suffering of trying to compulsively think our way out of pain.

The most basic suffering perhaps is that, again and again and again, things are not how we think they are supposed to be. There aren't supposed to be long lines, people aren't supposed to disappoint us, death, cancer, depression definitely shouldn't happen. We get buyer's remorse, we rationalize, we do things we think we shouldn't and then explain to ourselves or others why... focused internally or externally. We tell ourselves why things don't match up. "I'll start tomorrow." "Traffic is bad – maybe there's a football game." "I could never do that." We explain to our friend why it's OK to lie in this case. We justify, blame, or deny.

Not accepting the continuous reality of life is the ultimate addiction, the ultimate cognitive dissonance.

The thing I come back to over and over again: Whatever is happening now is how things are. It might be painful, but it is not a mistake, not an accident. It's life. The only appropriate response to how things are is an embrace.

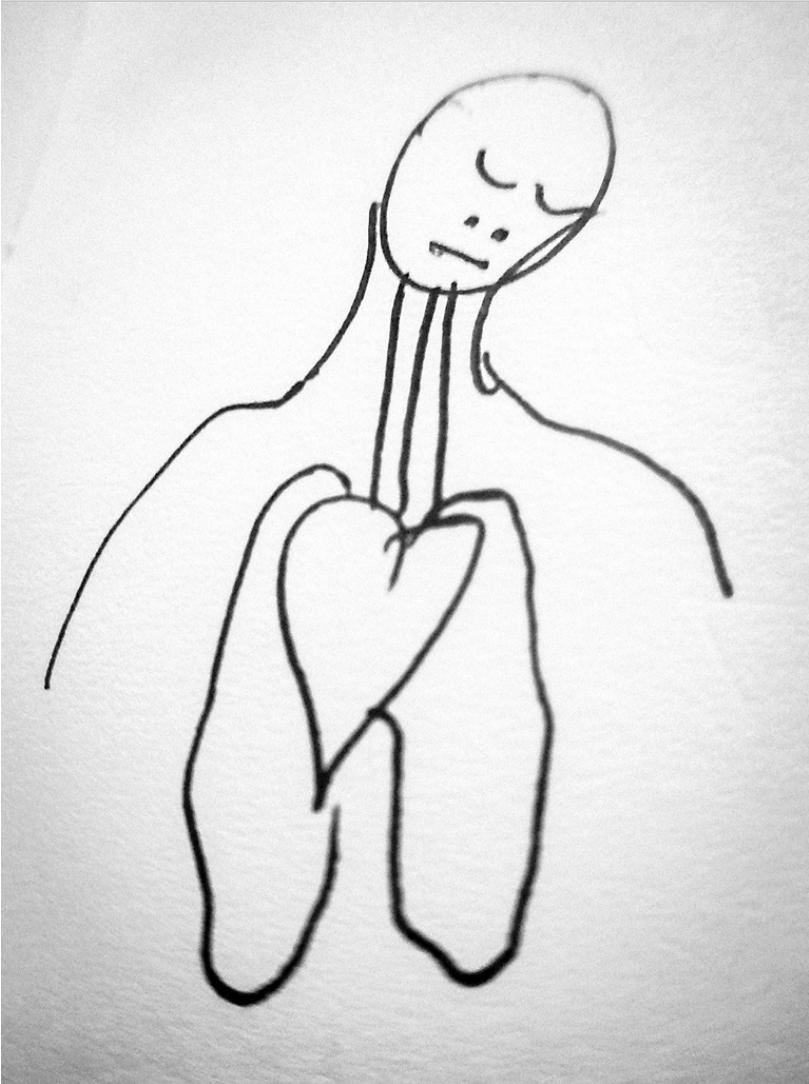
It's appropriate because it means we will stop fighting. Rather, we will accept and then in some way move toward positive change, but we put down the sword, we take off the blinders and the many-colored glasses and the veils. We shift the balance a little more toward what things are, what we are, and a little less toward what we simply wish them and ourselves to be.

Because we want to relieve suffering, because we want to progress – doesn't mean there is anything wrong. We must act and change things from the foundation of 'nothing is wrong'. And from that place we find – for at least that moment – the human body at peace with itself.

A flower falls, though we love it;
and a weed grows, though we do not love it.

Dogen

October 17: My point of view, drawn before I got the bad news.



October 2012: What can we ever really know?

October 2: **Functions of hair**

I stare, fascinated, at other people's eyebrows. It's astonishing how much they move around. My eyebrows probably look better than they ever have. After creating them, I dab on some hairspray with my finger. It shellacs them down so they last all day. They pass as hair eyebrows. Maybe I move them around, too.

I went outside yesterday and today with just a scarf on my head. It was 90-something degrees (34C), way too hot for the rug. You don't know about half the functions of your hair until you lose it. For one thing, hair softens the aging signs on your skin – on your face, on your arms, everywhere. You notice this when all or most of the hair is gone and wrinkles shout out. Hair is a buffer between your skin and the outside world. Your skin feels things more, it is truly naked. I remember reading *The Naked Ape* when I was in high school. That's me.

Your hair keeps the flow of mucus produced by your head from constantly dripping out of your nose. It keeps particulates out of your lungs. Eyelashes keep crap out of your eyes, including flakes from the crap you put on your eyelids that pretends you have eyelashes. Eyebrows make you look like something other than I, Robot, maybe, even, a human being.

Seems like my hair is likely to start growing again after about a month – maybe mid-November... In the meantime I bought another wig, identical to the main one I have except a little darker and redder.

October 4: **Prevalence**

Twelve million people in this country have cancer, according to the American Cancer Society. Around five million of those have breast or prostate cancer. Two or three of them have the kind of cancer that I was diagnosed with in December: cancer of the vagina. It took me a while to be able to say that. It sounds like a cruel joke. But that's gone now, and I hope the cancer in my lungs responds as well to treatment as my vagina/ bladder/ pelvic bones did. And I hope chemotherapy doesn't end up being the gift that keeps on giving – in terms of insomnia, dead nerves, and a loose cannon where there used to be bowels.

I got some more info yesterday – nothing about prognosis of course – about how things will progress, and what Dr M thinks about it all. The main thing is, she complimented my eyebrows.

My cancer staging has changed to “Metastatic Stage 4,” upgraded from “Stage 4b” (because now it involves only one organ, the lungs). My blood counts were better. Statistically, the odds that the cancer is, or will appear, elsewhere is high. That is to say, the chances of wiping out every single cancer cell is low. That's why they think of advanced stage cancer as a chronic illness, or rather, a chronic recurrence. It is not expected to go away, and in many cases it doesn't, or it comes

back. However, Dr M said she wouldn't be surprised if mine did go away. She also said my lung nodules are so small, they could have waited on the chemo, but doing it now might mean a long remission. She seemed very tuned in to quality of life issues, which was a comfort to me. She cut the intravenous dexamethasone (steroid) I get before the chemo drugs in half. Yay! Maybe I'll be able to sleep tomorrow night before 4am.

I have an appointment with her on October 22, so some time before then I will get a CT scan of my lungs, which will be able to determine if there are still tumors in my lungs, and if so, whether they have grown or shrunk or stayed the same. In about four months, a full PET scan, which looks for cancer of any size, anywhere. If everything stays clear, I will get scans (not sure which kind) every three to four months for a year or two.

I have chemo tomorrow, which in one sense is too bad because my feet have come back to life, and my digestion seems to be working normally, and my face isn't numb anymore! I'm fairly energetic, too. Dr M advised me to take preemptive meds (Colace or Docusate Sodium) against constipation, a word which means something very different to me than it did a year ago. That is, formerly an inconvenience to feeling like your body has mostly shut down in a torturous way. Despite the name of this blog, I don't really like talking about shit (or lack of it), but it's part of my experience now, so there it is. Will tomorrow be my last chemo ever?

October 6: **Smoothish sailing**

Laura and Bill were with me at chemo. I hadn't seen Bill in a while and we had a great chat, and in no time we were done (actual time is about five hours). It was a nice day, didn't pick up the laptop or a book the whole time. The fact that it was the last chemo for a while didn't feel that significant. I suppose it's because the infusion isn't where things end.

The chemo/drug routine before today has been that, before any actual chemotherapy, I was given among other things, 8mg oral dexamethazone, and 20 mg intravenously. By request, today I received no oral, and 10 by infusion. It is a completely different experience, much better. Kathy commented how different I was this time than last time. I am very tired, but it is better than the buzz I usually have, that keeps me awake most of the night. I was so wrecked that at Misha's I fell into a deep asleep in less than five minutes. Back home, Karunadevi made Laura and I an excellent dinner and we watched a movie.

I stopped taking prozac a couple of weeks ago. One less pill in my life feels good. I didn't use an estrogen patch for a week, but the world heated up again, so I reapplied for a week. (I know people say hot flashes are natural, but then again, so is cancer. And this is medical menopause, so it's not natural.) The further away I am from chemo day 1, the better I sleep, even occasionally without pharmaceutical or herbal aid. I am even tired of the herbs. Sometimes they are too difficult to digest, or it is too much fiber, and there are so many of

them. I'm supposed to take them three times a day but I often do two or one. I am so sick of drugs.

October 8: **Second half of today was crap**

After a fairly active morning (walking with Lo about a mile to Chloe's for breakfast and back, and taking her to the train station), and attempting a few tasks I decided to put off no longer, I could hardly move this afternoon. I lay in bed for many hours with my eyes closed, not sleeping, then watched an episode each of [Peep Show](#) and [Arrested Development](#) and played [Facebook Jeopardy](#).

Social Security requested a document from me – one I don't have – so I called Social Security (a different part) today to try to get a copy of it. Four or five times I listened to a message that said something like, "There are too many calls. Mondays and Tuesdays are super busy, so don't call then, and also don't call between 10am & 2pm on Wednesday through Friday."

I tried to figure out if my right headlight doesn't work because of a blown fuse, but the fusebox map seemed to be for another car. After pulling out around half of them, I couldn't even find the right fuse for the one that works.

So having not completed those two tasks, I started a third. I composed a letter to the National Personnel Records Center in Illinois, requesting my mom's medical records from Germany and France in 1963 to see if she was given DES during her pregnancy. But then

there was a 'drum issue' and only half the letter would print... On the positive side, I tried to do the things I've been putting off...

The energy drained from me and my feet turned numb with occasional needle-like pains. My guts cramp up occasionally. I feel completely wiped out.

I know a lot of people have the same symptoms I have – they get super tired but can't sleep, they are drenched in sweat, slowing down, hair falling out or growing in the wrong places, eyesight going to hell, digestion doesn't work, aches, pains, spaced out. These are some typical building blocks, or shall we say breaking-down blocks, of a human body aging. Apparently it can happen quickly, even to people younger than I, who don't have cancer. If I didn't have cancer and I were healthy like I thought I was a year ago, I wouldn't know this much about other people. But now I'm Sick with a capital S and people tell me their problems, problems the likes of which I have mostly been blissfully free from my entire life. I'm glad I know now.

Now I am thinking of what substances I'll take so I can sleep tonight. Ten mg of melatonin combined with Benadryl or something else sounds good. Heating pad on my feet, mmmm.

October 10: **Chemo lashes**

There are 1-2-3-4-5-6-7-8 eyelashes clustered in the middle of my right eyelid. This is chemotherapy. Feldenkrais this morning was good. All the pains and soreness were there, but there was also gentleness and by the end, some moments of happiness.

October 11: **What is truly prognostic?**

I like the word prognosis because it is related to the Sanskrit word prajña. But whereas the Greeks were referring to knowledge of what is to come, Buddhists were interested in what precedes knowledge. (This knowledge is courtesy of Red Pine in his book on the Heart Sutra.)

Today Misha asked, as she usually does, what day (since chemo) it is. It's Day 7. Honestly, I thought it was around Day 400. Laura only left a few days ago. It's only been a week since I had chemo. Perhaps another week and I'll be ship-shape. Or not. But for a few days my suffering seemed to be eternal. Anyway, she suggested peach kernel pills, which immediately solved my digestive problem. She also suggested I see her twice next week if the suffering does not abate, which I will do.

On Oct 18, at 11am, I will have a chest CT scan. I'll find out, again, whether the treatment worked for a particular area of my body. Regarding the whole optimism/ pessimism issue: Since no matter what this scan shows, it doesn't mean anything about forever, or even the next six months, the significance of it has waned, in my mind. It's just another step. What's truly predictive are all the scans I get in the next 5-10 years.

October 12: **An optimistic thought**

Today instead of counting my eyelashes, I thought, Wow, I don't have a moustache to deal with, cool. Or toe hair, for that matter. I managed

to go to Jane's pilates/cancer class this morning. Later I had a reiki session from Tania. It was great, very similar to how I feel when I'm resting with the needles at Misha's, or doing a body scan. What is healing? Who knows. But there's something about a deeply nourishing rest that seems to be part of it.

October 14: **Navigating a shitty mood**

Some things occurred to me as I walked up 24th Street this evening, watching the sky turn pink. It occurred to me that I've been complaining more lately, generally with a shittier attitude. This is somehow linked to frustration with waiting, with being in limbo land. It further occurred to me that there is nothing to wait for. The scan I will get only provides temporary information. In that way, it is like all information. Any information one gets sheds light on now. This is one of the slow lessons of cancer. Slow for me anyway. There's very little in the way of certainty, of 0's and 1's. This morning I had breakfast at Radish with Anushka, who reminded me of this. The info you get doesn't last. Cancer is sneaky and subtle, as are lots of other conditions of life.

People have different responses to me complaining. Most people are thinking – whether they actually say it or not: Yeah, you have fucking cancer, you're damn right you're complaining, because cancer sucks and you shouldn't have gotten it. I should have gotten it because I am a sickly bastard who does not take care of him- or herself. But you're the one who got it, and you've had two rounds of treatment, you still don't know what your status is, and all that sucks. Of course you're

sick of it. Others don't seem to be interested in my complaints. Strangely, when people are sympathetic, I don't notice as much that I am complaining.

It seems to me that there is no point in waiting. What can we ever really know? Why resent this moment for not being an imaginary later moment?

This morning I talked to Trebor, who is living with his family in Berlin for a year. I'm sorry I haven't seen his little girls in such a long time. Rosa turned five today and the other, Emma, is one. One thing we talked about is how sometimes you can realize that you're in ideal conditions, and that the grouching is not really about external things.

What to recommend or get for your female pals with cancer

Most headgear for cancer patients is ugly. I got a "sleek turban" in dark blue, from Jazz Up Designer Headwear. It's cute. If you buy a Sleek Turban for your pal with cancer, start with buying one in a plain color that will match the colors she tends to wear, and see if it works for her. The problem with wigs and hats is they all seem to be created with room for hair in them, so if you don't have hair there's extra space, or they're droopy. Point being that the Sleek Turban might not work for someone with a head smaller than mine. Or you could get 'em something to fill in the empty space with. I have no idea how people do that, but no doubt there's some kind of gadget.

I miss my hair, and am looking forward to its return, though I probably have at least another month before it even starts. All kinds a crap is

getting into my eyes and nose because I lack the hair shield. Hair is awesome.

October 16: **Hold your breath for nothing**

OMG I felt great today. My feet are still a bit numb, but who cares? It's because I have decided to stop waiting. There is nothing to wait for. And no one to wait for it. Yeah! I have broken the cycle of the end-of-treatment blues. On October 23, at 11:30am, I'll find out the results of my scan. It will be one milestone in the series of cancer-related milestones that structure the current configuration of my life. But one cannot hold one's breath for milestones. There is too much missed, even when nothing is happening.

Cancer gives me lessons, all of which apply to regular life, too. It's just that they have been forced on me, because uncertainty, impermanence, and death dropped out of theory into reality. Like the folks learning to meditate to reduce stress vs. the folks learning to meditate because they are in jail, or a doctor has told them their life is pretty much over. And there are also smaller deaths... Like one's identity as a healthy person. Like the sense of oneself as productive. Like whoever you are when you have hair, you're someone else, kind of, without it. Like the unconscious assumption that things as they are right now – health, or sickness – last forever.

I had a chat today with B, who is a social worker in palliative care. Basically for dying people, part of an advanced illness coordinated care program, which I qualify for because of my staging (Stage 4). I felt

so happy, I was sorry not to feel worse when I spoke to her, give her something to do. But it was cool. She helps people with a lot of different things. She had an interesting take on 'the bucket list': What is important to me? She helps with planning around what is important, and ways to make difficult decisions, and communicate about them. Awesome.

I think a lot of the trouble I have had came from not being able to sleep. I took two wonderful naps over the weekend, something I haven't been able to do in what feels like a very long time. I'm convinced that taking anything in order to sleep wrecks my day, but I don't know if it wrecks my day more than not sleeping does. And this is mostly about non-prescription sleep aids. Anyway I've cut way down on the pills in general. Sadly this meant I stopped using the estrogen patch, so now the world is boiling hot again, bummer. I started using it again over a week ago but the temperature remains tropical.

October 17: **Symptoms/nadir**

Very tired today. Stayed in bed much of the day but managed a walk to Whole Foods in Snowy Valley to give my regular donation. According to Google maps it's 1.8 miles roundtrip. A sore in my mouth on the left, the problematic side of my facial symmetry, which is also numb off and on. Numb feet, but stabbing pains seem to have gone away. Sacrum/hip joints very sore, possibly from pilates class Friday. And that's about it, not too bad. I wish I had more philosophy for you.

Today I was reading more of *Turning Suffering Inside Out*, an excellent Dharma book about suffering. Here is a section:

From my experience with my own body and from observing other people I teach, I have come to believe that there is some biochemical concomitant of active, conscious, deliberate attempts to heal ourselves, beginning with relaxation techniques that seem to enable us to pick up the body's signals through the garble of goal-oriented thoughts and panic over our condition.

Which seems a bit complicated. I guess what's she's saying is that (she believes) conscious attempts at self-healing, which begin with relaxation, are followed by physical healing. Lungs getting scanned tomorrow.

P.S. I looked it up and I am in the 'nadir' part of the chemo cycle. Amen.

Shaman II

A couple of weeks ago I went to see my friend Alan the shaman. Alan had said some things last time I saw him (June) that didn't sit well with me, about various things including what caused the cancer that I have. This is one of the things I followed up with him and we had a great talk for about an hour and half. Alan has no interest in or faith in (or much knowledge of) science, genetics, etc. He said his views are what allow him to do the work he does. It's interesting how different people have a 'science' or 'spiritual' orientation. I think I have a combination of both. I think there are purely physical/biological causes

to things, and there are also mental or karmic causes. It is difficult to determine causes, but I try to get all the types of conditions working in my favor!

I have a lot of respect for Alan in his vocation as a healer. Last time I saw him I was more motivated to 'pick up the ball' again and be more careful about what I eat. He has been very kind and supportive of me. This time, and last time, he guided me through a relaxation/visualization and emailed the recording to me. I left feeling grateful and very deeply relaxed.

Bad news

I wrote to Dr M asking about the results of my CT scan. She replied:

Ms. Cullen –

I was surprised by the results of your CT as you have been doing so well. Unfortunately, the CT suggests some of the nodules are larger and that there are a few new nodules. The report is attached for your review and I will give you a paper copy when we meet next week. I do not think this should prompt you to change your upcoming trip in October/November. We can discuss the pros/cons of travel in December/January when we meet.

October 19: **Rather shocking**

As a friend excellently summed it up in an email today,
Shit, that blows. Everyone seems to be surprised. Not least of all, my oncologist and I. How do I want to spend my time? Will I go to Mexico

on October 30? It's all up in the air now. I'll decide by Tuesday when I talk to the doc.

I'm assuming that chemotherapy is what western medicine will have to offer at this point, which is crap. Well, if it works it's not crap. Mine seems not to have had any effect at all. Come to think of it, what my body responded to so well in the first round of treatment was radiation (chemotherapy aspect was minor).

At this point the prospects seem dire. It now seems much more likely that cancer and chemotherapy are permanent (as it were) parts of my life. Which, as already articulated, blows. Presumably I'll get used to the idea as I have everything else? Not sure about that. I'm remembering the social worker talking about someone who had lived for ten years with some kind of advanced stage gynecological cancer. And been on chemotherapy the whole time. Yuck.

I figured the reason I've been so tired and cravey is because of the chemotherapy. But in light of current info, I think back to December of last year when I was first diagnosed, I was having crushing sugar cravings, and a lot of fatigue. That was because of cancer. Maybe this time, too. Maybe it seems fairly normal to have sugar cravings, everyone has them. But these cravings are more intense than any others I have experienced in my life. It's also true that it might not be related to cancer, who knows? Could just be related to fatigue, which also may or may not be related to cancer.

October 23: **Random thoughts and questions**

I look in the mirror today and see the skin of Tommy Lee Jones. What's the difference between a nodule and a tumor? They're both abnormal swellings. A nodule is smaller. Nodus in Latin means 'knot'. Tumere means 'to swell.'

Jules came up last night and we watched two good movies: The Dictator, very funny, and Senna, an excellent sweet documentary about the Brazilian race car driver Ayrton Senna. I want to visit Brazil. Egypt. Norway. Or do I? What about alternative treatments? Two weeks of veg. juice and wheat grass in Mexico? An Ayurvedic retreat in India?... Or what? My bucket list (what is important) – What is on it?

Here's what Tenzin Palmo, who did a 12-year solitary retreat in a cave near a Tibetan village, said in an interview about my two best friends/foes, Hope and Fear:

I remember one spring when the snow melted and the cave became completely flooded and soaking wet. I also had a cold. I was feeling extremely not well, and I was thinking, "They're right what they said about living in caves. Who wants to live in this horrible wet place!" I was feeling horrible, it was cold and miserable and still snowing. And then I suddenly thought, "Are you still looking for happiness in samsara? Didn't [the] Buddha say something about dukkha, suffering?" And when I thought that, I suddenly thought, "Yes, it doesn't matter, it really doesn't matter. Samsara is dukkha so it's fine, there's no problem. Why expect happiness? If happiness is there, happiness is there; if

happiness isn't there, what do you expect anyway? It really doesn't matter!" When I felt that – it was something not just in the head at all, it was really in my heart – this whole weight just went away: hope and fear. We're always hoping that everything will be pleasant somehow, we're always fearing that it won't be. And in that moment the whole thing dropped away, and it just didn't matter. This was an enormous relief...

I've been noticing that I am not experiencing that relief. My mind cycles through 'realistic' hope- or fear-induced scenarios and plans, creating suffering for itself. (On days like this, Sartre's comment, "Hell is other people", seems completely insane.) The wheel spins another time and lands on Uncertainty, which in its pure state can be a great relief. Or it sinks its teeth into my lungs.

'Being well (even when you're sick)' teaches MBSR (Mindfulness Based Stress Reduction) specifically for people with cancer. I found some of it boring, some of it good. I like the stories about the author's own life dealing with cancer. In general, I can dig a good cancer memoir. It's like being in a support group, only more entertaining and maybe not as useful in terms of practical information.

I think I'll go to Mexico. There's an eight day retreat for women who've requested ordination, on the theme of the "Mythic Context." If it were any other theme I don't think I'd go, but that one is right up my street.

I went for a three or so mile walk with Tong in Tilden Park. It was beautiful. It felt good to walk on dirt rather than cement, but toward

the end my toes got very numb (was tripping a lot) and I got very tired. Same thing happened today with Lisa at Lands End. Before that she helped me do some errands, which was awesome.

October 24: **(A bit) better news**

It was great talking to Dr M. I was figuring she'd want to dose me up on chemotherapy as soon as possible, maybe in December. Fact is, she has no idea what kind of chemotherapy to give me, I don't have any actual cancer symptoms yet, and anyway she knows the importance of breaks. She says that no one knows or has anything definite on what will work for my type of cancer.

As I have been told since Day 1, I have a very rare type of cancer, about which data is scarce. My treatments so far have been based on similar gynecological cancers – uterine, ovarian, or cervical – which are also adenocarcinomas (same cell type). She explained to me how the chemotherapy I just got made sense for me, something about “platinum sensitive” gyn cancers. It brought home to me just how much of an educated guessing game all this is for the oncologists. She also said that at the time of my original treatment back in January I probably already had micro metastases in my lungs.

She's going to take the time I'm in Mexico to figure something out. I could barely understand what she was saying about that. Something about doing various tests on the original tissue from the biopsy, looking for 'markers'. Padmatara recorded most of the convo which was very handy in writing this, but I am too tired right now to listen to

the specifics about the kind of research she will do. Listening to the recording again really helps in general though. Oncologists seem to talk fast. However Danamaya commented what a good doctor and communicator she is.

As to the condition of my lungs: while the nodules have grown and there are more of them, they are all still very small and seem to be growing slowly. There are 3-4 nodules that are very small, and 3-4 that are easy to see. The 8-10 nodules I talked about before were I think Dr K's guess; the scan reports never gave a total detected number. In five or six months the width of a nodule in my left lung grew about 3.1mm, or 1/10 of an inch. This is one of the bigger ones. Dr M said, "There is a huge amount of normal lung." So this is a slow-growing cancer. (Misha says slow-growing cancers are more resistant to chemotherapy. Need to ask about that.) What is a fast-growing cancer? The size of a small-cell lung cancer tumor could double in two weeks.

I had thought that it wouldn't be possible for me to get radiation again, but apparently that depends on the body part. For the lungs it would be fine, though she spoke of it in terms of "symptom control" rather than survival. If one nodule, for example, started growing more quickly and causing symptoms. Symptoms to look out for: shortness of breath, a cough, fatigue, or weight loss. I remember a main complaint back in November of last year, when I first was moved to go to a doctor, was fatigue.

I will get an x-ray in early December. (Apparently x-rays expose you to 1/1000 the radiation of a CT scan.) What about travel? Depends on how I feel. She will be looking for clinical trials for new drugs, and suggested I look around as well. My health plan will cover costs of participating in U.S. based Phase 2 trials. (Phase 1 just determines dosage.) She suggested choosing a location near a support system. My initial search showed that most questionnaires require one to choose the cancer type, and my cancer type is not one of the options.

Listening a few days ago to the recording of the talk I gave to the Gay Fellowship completely changed my attitude! I still don't know what's going to happen. I can still enjoy my life...

October 25: **Cyberknife**

A little more about the meeting with Dr M. As did Dr S, she seemed to panic a bit when she saw I had two pals with me. I think they expect to be detained by random inane questions. The first thing she said was that she had spent quite a lot of time with me before but this time she only had twenty minutes, she had a meeting to go to, but then she stayed for forty. Why don't doctors just know that my friends are cool?

Dr M mentioned, in passing, "**CyberKnife**" treatment. It's super-precise radiation, "a pain-free, non-surgical option for patients who have inoperable or surgically complex tumors, or who may be looking for an alternative to surgery". I am starting to look for clinical trials. Most of them seem to be for chemos, which I am not at all enthused about. At

this point CyberKnife seems much more promising, since radiation worked so well already, and chemo, for me, is such a crap shoot.

Misha and juice fasting

I told Misha I'd gotten discouraged and wasn't taking the herbs as much. She said the herbs might be the reason the nodules are growing slowly. I asked her what she thought about me doing a juice fast. She said for 90% of her patients she would say no, but for me she thinks it'd be all right. (It's because my condition according to Traditional Chinese Medicine involves 'excess' and 'heat' whereas most people are 'deficient' and 'cold'. Raw vegetables are cold.) She suggested I consider consulting with Dr A at his Center for Integrative Medicine near Chicago. Not psyched about that just because it will be very expensive and don't feel confident that it would help. At least from the Western medical point of view it's treatment for my specific cancer that is the mystery and presumably he doesn't know any more about that than my oncologist does. He might know some general things that could be helpful. Just not sure I need to go to Chicago for that.

Palliative care

It was a very good meeting today, very interesting. However, I don't have the energy to write it all up. I will say that B described the 'marker' mystery as genetic markers that can suggest or predict someone's response to a particular chemotherapy. (That it won't work at all, or which ones might be better for a particular person.)

Online forums

Though it was not my plan, I've been reading online forums for hours. Almost everything folks who had experienced CyberKnife had to say about it was positive. One woman mentioned there were 'the usual' side effects but she didn't say what they were. One guy said the only side effect he had was fatigue. Many people live in places they can't get it, and apparently some insurance won't pay for it.

Then the radiation gets delivered from all these different angles, I think that's why surrounding tissue isn't damaged. When radiation is being delivered to lungs, the beam locks onto the tumor and moves with your breathing. Cool. Seems too good to be true...

October 28: **Hasta la vista, baby**

I leave for Mexico on Tuesday. I drove down here to the OC yesterday while listening to Wicked (although tape #11, which is when she meets Dorothy at last, was tragically broken) and then to Patti Smith's memoir about her life with Robert Mapplethorpe, Just Kids. The seven hour drive south flew by. It's nice to visit my dad and Chris in this big house. Among other things, they are out of touch with popular culture in different ways than I am.

It's been three weeks + 1 day since my last chemotherapy. And for the last two nights I have been able to sleep, no problem. Yay! My feet are still numb (maybe a bit less), my hair is still falling out, and there are various other issues. Boooo! I'd love not to have any more chemotherapy.

An email I got this morning

We have all heard of the stories of people with cancer being grateful that they have been able to focus on what is important. I read in your blog of a friend who commended you on your attitude while having cancer. The problem is that before you had cancer, you were already able to have a more positive attitude in the worst of times than anyone I've known. You didn't need cancer for that because you already had that. Maybe you see internal growth. What I see is the strengths you already had serving you well. That is my view from the cheap seats.

I like the last line. Anyway, aside from horn blowing... I'm noticing some things about my psychology. Like how often when someone helps me in some way, I get a vague feeling that I am taking advantage of them – a very strong need to feel independent, perhaps invulnerable. I often have a positive attitude, as my friend above says. It's also true that when I don't, I feel that I should. Seems to be hard for me to accept my own sadness.

October 30: **Crap. About. Cyberknife.**

I got a bummer email from Dr M (though I am glad to have the info!): "You have too many lesions for Cyberknife to be a good option..." I don't feel like I can do chemotherapy again, especially when it seems so unlikely to work. Must try not to fill in the blanks about what will happen or what I will do. That will be my practice for the next month.

Ode to Jacques Cousteau

16 February 2009

it's hard to imagine
how we survived the dark days
before the internet.
but we had jacques cousteau

who brought us, just children,
with him on his adventures

who spoke english to us
though it clearly tortured his throat.

jacques cousteau was my pied piper.

i am sinking with him
down & down & down

into a dark world
where we will shine our lights.

Nov 25: A dead pelican on Newport Beach (and me)

Photo, Jeff Perrin



November 2012: Heal thyself

November 1: **Alternative therapies (post from México D.F.)**

Should I be seeking out alternative treatments during this time “between treatments” rather than traveling? I can’t help but obsess over this question, and others. But the retreat will give me something else to focus on. In the meantime I’ve had a lovely two nights and one day with Lena and Maya here in Mexico City. And Dawn arrived tonight. Tomorrow morning Lena, Dawn and I will head to the retreat.

November 11: **In Mexico, tuna is a fruit**

I am in Mexico City, staying at Lena and Maya’s in Tecamachalco. Maya made us the most amazing dinner last night! Georgian food (fried eggplant rolled up with walnut paste) and vegetarian sushi.

The retreat was wonderful. There were over 50 women, around half from the US and Canada and half Mexican women, at a beautiful and spacious retreat center in Morelos state, called Chintámani. I felt very sad, or at least cried easily, the first couple of days. I tried to welcome it, I have cried so little this year. The first day of the retreat was the Day of the Dead, which I love, but I felt too weepy to participate much. I very much enjoyed leading a Vajrasattva puja (ritual).

Trying to speak and understand Spanish to chat with folks on the retreat was a bit frustrating for me. (For events everything was translated.) By the end my Spanish had come back a bit. I have been

told I have a good accent in Spanish, but unfortunately I don't know many words and am trapped in the present tense.

Heading for San Miguel de Allende tomorrow morning. Las cosas como son.

November 13: **The witch of the Mexico City Buddhist Center**

My hair is growing back, it is awesome. At this point it sorta looks like weird white fuzz in a bald man's hair pattern, but that's OK, I'll take it. I'm in San Miguel de Allende sitting in my little enclosed patio. Kathy and I managed a Skype call last night. She was wondering why I'm so anti-chemo (she didn't put it that way). In case that is not clear to others: it is not that I am against getting more chemo per se, more that they had no idea whether or not the last one was going to work, and they will have no idea whether the next one will either. It is an educated craps shoot. And it's not like you just go get a shot that may or may not work. Your veins get hooked up to an infusion machine for a total of about 30 hours, and the whole treatment (which I will remind you, didn't do anything other than cause side effects!) took between five and six months. And you may have some of the side effects for the rest of your life. I guess Dr M will want to start chemo again if or when I start getting symptoms, and/or if the nodules get bigger. In short, even though it's much better than it was 25 years ago, chemo still blows. When it doesn't work.

I have five full days here to focus on writing. It's ideal conditions except for the food. White bread, no veg, and the fresh food you buy is used

by Montezuma as a way to exact revenge. Eating the awesome food on retreat or at Maya's was much easier! I bought some stuff at a grocery this morning, including carrots which I rinse with hot green tea.

I wanted to write about the time I spent with Dayachandra on the retreat. I met her last time I was in Mexico, over a decade ago, I think her name was Cecilia then. She spoke no English and I spoke more Spanish than I do now. Somehow we loved each other as if we had always been friends. We are always delighted to see each other. Last time was at the Order reunion in the UK. Thankfully she had learned some English; my Spanish was complete crap. Turns out she does a lot of what she calls "energy therapy". She seems to be something of a shaman. We had a wonderful conversation; we now both speak Spanglish! She told me to talk to my cells, that cells are intelligent. To ask them to revert to their healthy state. They will respond. They are my friend. She also drew a diagram involving two triangles and a human body that I didn't understand at all.

But if my cells are healthy, how did they become cancerous? Did cancer hijack them? If so, do they get to choose? Although these kinds of questions are perhaps irrelevant to this kind of conversation, it's how I think, I can't help it. I need to have an angle on it that makes sense to me. So I've been doing it. I ask my cells to breathe, to go back to breathing. Dayachandra said she would do it also, from a distance. She also said I would be all right...

I am motivated to use my mind to try to heal myself. Kathy mentioned a time when her four year old son had a virus that the doctor didn't understand. A friend advised her to put her hands on his knees and say silently, Heal Thyself. So I do that too. I ask my lungs to revert to their natural healthy state, which is a state of breathing, of transferring oxygen. I say, Heal Thyself, Heal Thyself.

November 15: **Post from San Miguel**

I was approved yesterday as Dawn's preceptor, yay! So if all the other ducks get into a row, I'll be flying to Spain in May to ordain her.

Having a great time writing here. I wish I were staying a couple of weeks and I'd take some time to look around. I stayed at the public library all day yesterday and got a lot done. Well, I didn't get a lot done, writing is rather slow for me, but anyway, worked on it for five or more hours. And had a burrito there for lunch, possibly the best I've ever had, and a nice salad with shredded raw beets. I know one is not supposed to eat raw veg here, but I am not cautious, that's probably why I have cancer. (Joke. Broma.)

November 17: **WAH-na-WAH-toe**

Did a short day trip to Guanajuato yesterday, a 500 year old city. It was like being in Spain, only with brighter colors, graffiti, mariachis, and Mexican food! The taxi driver said they call San Miguel "Gringolandia"... but it's good and quiet for writing. In the main square an Australian woman gave me a flyer for an Indian restaurant, where I went to eat. I bought some sprouted bread from them. She

said it had no sugar in it but I doubted it. Anyway it was better than anything else I've had lately.

Should I stop saying my toes are numb? Perhaps I'll let you know if they're ever not numb. I wear double wool socks whenever I can. (Wondering if the numbness is only noticeable when I walk down stairs.) Sadly I left the glutamine that's supposed to help (don't know if it actually does) at home. Also, was shitting blood yesterday, the effect of eating little fiber on my irradiated guts... I think my December holiday will have to include a kitchen.

November 18: **Radiation redux?**

I am reading Eat to Live by Dr Joel Furhman. It makes sense. Well. It may only be interesting if you are particularly concerned with your health, or with losing weight. The health problems he mentions are mostly a result of the 'modern American diet' (MAD) which I have not had for a long time, and about health problems other than cancer, but I thought this was interesting:

The link between thinness and longevity, and obesity and a shorter lifespan, is concrete. Another important consideration in other animal studies is that fat and protein restriction have an additional effect on lengthening life span. Apparently, higher fat and higher protein intake promotes hormone production, speeds up reproductive readiness and other indicates of aging, and promotes the growth of certain tumors. For example, excess protein intake has been shown to raise insulin-like growth factor

(ICF-1) levels, which are linked to higher rates of prostate and breast cancer.

The notes reveal that some of these studies were around hormone sensitive cancers (not what I have.) I have certainly been increasingly overweight, which I'm not prepared to say "caused" my cancer, but OTOH it couldn't have helped. I want to get with the Fuhrman plan once I get back to my dad's.

The last few days I've felt that the side effects from the radiation are re-emerging. My hips feel very tight and sore, and when I try to stretch them a bit, they hurt more later. I am also very tired the last few days. Is it from the food? Dr Fuhrman might say yes. Actually I think another factor might have been the writing, or at least, sitting still for hours at a time.

November 20: **Cheeseball cancer movie**

I'm in the bigger upstairs room at my dad's, watching a not-great but nevertheless tear-jerking Hallmark Channel cancer movie called Living Out Loud. Ever notice that chemo patients in movies only lose the hair on their head? They have perfect hair-based eyebrows.

I was going to transcribe a bunch of quotes from Dr Fuhrman's book, but don't have the wherewithal. Anyway, I'm a vegetarian again. The book is basically a summary of about 2,000 studies related to nutrition, and a suggested fresh vegetable and fruit intensive nutritional program. He cites numerous links between fat and protein – especially but not only animal fat and protein – and disease. (I am already

avoiding most of the types of foods he suggests but not eating enough veg.)

November 21: **Gramma's squash pie**

I'm at my dad's watching a James Bond movie, *The Man with the Golden Gun*, 1974. Currently the midget who played Tattoo on *Fantasy Island* is pelting Roger Moore with bottles of champagne. I just made a huge pot of mashed potatoes. All I put in it is peeled potatoes, some of the water I boiled them in, and garlic. Don't tell anyone.

Today I got up early and drove to Banning to pick up my mom for Thanksgiving. She is doing well. She seems in good spirits and her memory doesn't seem as bad as it sometimes is. My dad is slowing down a lot.

I've felt rather energetic since I got here, not that there aren't issues, but having energy is cool. I also felt a bit crabby today for some reason, possibly from not meditating in three days due to early morning duties. Dinner tonight was at Souplantation (virtually equivalent to Fresh Choice in Northern California). I love a big salad with lots of different veg (no bread, dessert or pasta!)

Laura emailed me some info about the tumor-reducing potential of cannabinoids. There's a clinical trial for brain cancer at UCSD. It's interesting but I don't feel hopeful about being able to find a clinical trial. Logged 8,000 steps on my pedometer today. OK. Friends and 30 Rock reruns or bed...

November 25: **Fuzzy**

My health is slowly improving. I worry that my toes will be numb and cold forever, but very little of forever has passed since I had chemotherapy, so maybe not. Wait and see. I sleep well, just like I did before all this came to pass. My head is getting fuzzy with hair, but not in all the places that hair used to grow on my head. Like in the female sideburn area, there is nothing.

OK, time for bed. Getting up at 4:30am to drive home missing rush hour in L.A...

November 27: **How I am now**

Monday I didn't count steps, was mostly driving, but probably there were very few. Also ate some crap food (popcorn, Trader Joe's cheetos, and stuff with fake sugar in it!) Saw the excellent Argo with Jules. I arrived home this morning. I was thinking about all the bad news I got in the beginning of this ordeal. Every time I went to a new doctor I got more bad news. First there's a tumor, then it's in the bladder, then it's in lymph node(s), then it's in the bones, then it's stage 2, then it's stage 4, then it's stage 4b, and there is almost no information about treatment. When I would hear new info about the extent of the disease, I'd be shocked for a few minutes, or a few hours. It would pass, and things would somehow feel "normal".

I realized that this time it's taken me several weeks to get used to the news that the last round of chemotherapy didn't work, and that the way forward is totally unknown, and that now maybe the cancer in my

lungs will kill me. The odds of finding a clinical trial seem slim. The prospect of my death is more real now. I said in the beginning that I was OK with dying if that's what was going to happen. I'm not sure about that now. I guess I'll know when it happens.

I suppose in my life I have kept my distance from friends and family in some way. I remember telling someone years ago that the reason I didn't want to have children was that I didn't want to be tied to this earth. Mostly it wasn't a conscious philosophy. But I feel like having a kind of cancer that's full of question marks has caused me to be more connected with people, and feel more of the pain of potentially being separated from them.

November 29: **Lifeguard**

I had a very strong dream last night about my first husband Michael. An influence in the dream must have been Patti Smith's memoir *Just Kids*, which ended with death and AIDS. Michael and I were young, in a relationship, and he found out he had AIDS. The only thing about the dream I really remember is crying, and begging him not to die. In non-dream life, this is not something I would do. It's more human in some way, more unrestrained.

It's funny lately how in dreams I have so much love for him, more than I ever loved him in person. What's the deal? Is it some early part of myself? Am I dropping the jadedness that came from that relationship? Am I begging myself not to die?

If you love animals

30 September 2008

They are not brethren, they are not underlings. They are other nations, caught with ourselves in the net of life and time, fellow prisoners of the splendor and travail of the earth.

Henry Beston

Vegetarianism is a subject even I don't particularly like. But I would like to say the following:

- If you love animals, the greatest single thing you can do for them is to stop eating them and supporting the industries that treat them so cruelly.
- Everything that lives, with the exception of some very unhappy people and maybe some lemmings, wants to continue living. Is it right for us to deprive another being of their life when it is not a necessity for us? Or to give our money to someone else, or indeed a huge multi-national corporation, depriving beings of their life?
- Do you think you could continue eating animals if you visited a slaughterhouse?
- We think of eating a cow or a fish as totally different from, for example, eating a dog. But aren't these things essentially the same?

Many people, because of the influence of the dairy industry I suspect, think that they cannot get enough protein without eating animals. This is just a lie. Our diseases are diseases of affluence – obesity, diabetes, heart disease. All these have been linked with meat-eating. The cattle industry is also a large factor in climate change. It has been estimated up to 20% of greenhouse gases come from livestock.

So I ask that you bring attention to this area of your life. The decision is not necessarily 'do I become a vegetarian?', but 'how can I bring more awareness into eating?' Do I eat meat when I could just as easily and happily make a vegetarian choice? How can I be more ethical and compassionate in the food I choose?

April 28: Here's a nice photo with Dayamudra during a Sunday wander around the neighborhood, which was wonderfully warm.



December 2012: Die while you are alive

December 1: **A Homecoming, by Wendell Berry**

One faith is bondage. Two
are free. In the trust
of old love, cultivation shows
a dark graceful wilderness
at its heart. Wild
in that wilderness, we roam
the distances of our faith,
safe beyond the bounds
of what we know. O love,
open. Show me
my country. Take me home.

December 2: **Die while you are alive**

Die while you are alive and be absolutely dead, then do whatever you want.

Zen Master Bunan

A thought occurred to me a while ago, and it has reappeared. It's speculation – pure hell for the question mark cancer patient – but there it is. I thought: If I had been sexually active recently, chances are I would not be in the situation I am in. This is because penetrative sex would have been painful, and I would have gone to a doctor, and could have discovered the cancer at a much earlier stage. Which would put me, now, in a much less smelly kettle of fish. Obviously, it does not help to think in this way. Still, sometimes I can't resist it. It might also be true that if I had never done X, or visited Y, I never would have gotten cancer at all. But then, there is how it actually happened. That's all there really is. Part of me cannot fully get that.

My friend Mike asked me, “Do you think it's easier to go through this because on some level you actually want to die?” This was a brilliant question. From the time I was about ten years old to my mid-twenties, I contemplated suicide during periods of severe depression. That time also roughly corresponds to my drug taking AKA self-medicating years. Until recently the depression I was so prone to had been slowly weakening. It was getting milder and lasting for shorter and shorter lengths of time, sometimes only a few hours. Then when I was about 47, and by some measures happier than ever before, it

kicked in again with a vengeance. It was surprising. I could not find a psychological cause that made sense. I figured the origin was either karmic or hormonal (or both!) Long story short, a wise nurse practitioner suggested a low dosage of fluoxetine (AKA Prozac) which apparently helps with several perimenopausal problems including mood swings. And from the first day I took it, those troubles were over. (I have since stopped taking it and am not depressed anymore, probably thanks to medical menopause.)

Going back to Mike's question: Is it easier to go through this because I actually want to die (or at least because I have spent a fair amount of time wanting to die?) Probably. And in ways not related to depression and suicide, I have somehow kept life at arm's length, ready to let it go. I have been jaded in some way, unable to fully embrace life. And I always thought of my resistance to life – my taking or leaving of life – again, probably not consciously, as being my decision. But now the part about having a choice has been removed, because life, now, is obviously in charge, not me. That has made me love and appreciate it in a way that before was mostly theoretical.

Here's my email version of a "disease elevator speech". Everyone should have one! I composed it yesterday when asked about my health by our MBSR venue landlady (Bill and I are offering a course in February). A year ago I had canceled my reservation with her, told her I had Stage 4b cancer.

Currently I am feeling very healthy. The original cancer that I had – and there was a lot of it – is totally gone. I still have stage 4 cancer (metastases in my lungs) which may end up killing me (or not!) but I do not have any symptoms now, just recovering from last round of chemo (which, of course, didn't work!) So again I don't know how long I have to live – but much of the time that helps me enjoy my life, take good care of myself, and love people more, so it's all right.

I think it's a pretty good summary, although maybe a bit too rosy? For instance, it doesn't always help me enjoy my life, it sometimes fills me with sadness and confusion. There's only one thing on my bucket list: I want to finish this memoir as a book.

December 5: **My heart hurts**

Julie and I met with Dr O yesterday. I remembered how fast he talks. I told him about my current symptoms. One of them is that my heart kind of hurts. I'm not certain it's not emotional, but thought I should mention it. All of my recurring pelvic troubles are longer term side-effects of the radiation. I remember a worksheet with lists of short term and long term side-effects. I didn't read the long term column. When I asked how scarring could go on for so long he said it's not really scarring. It's fibrosis, a late effect of radiation. It means that the fibers stiffen and contract. So I need to keep stretching. It would seem that my hips will now always default to being tight.

He said 1-2% of patients who receive radiation treatment develop cancer in the radiated area in an average of 8-10 years. So lots of cancer treatment isn't curing, but postponing. He said they didn't do full-on radiation in my bones so if it is needed again for pain relief they could do more. The specific reason they can't do CyberKnife (focused radiation) in my lungs is that the radiation kills part of the lung tissue, so if it's all over your lungs, you could have shortness of breath your whole life. He said to email him if I have questions about radiation. Such a lovely man.

December 6: **Sitting with uncertainty**

On a cancer blog by Bonnie Gintis she cites a study done by a PhD candidate at UC Berkeley about spontaneous remissions of cancer. Six things were found in those who thrived:

Deepening one's spirituality

Trusting in intuition regarding health decisions

Releasing negative and/or repressed emotions

Feeling love/joy/happiness

Changing one's diet

Taking herbal/vitamin supplements

When I read stuff like this I think, What about the people who did these things who did not experience spontaneous remission? What about the people who did none of these things who experienced spontaneous remission? Well. Those people weren't the subject of the

study. I do think that a lot of what one hears about cancer is bullshit, though not necessarily on purpose. A friend of a friend drank kale smoothies/ate a lot of lemon drops/____ and was completely cured! It isn't that I'm not happy for these people, I just don't believe that they have complete understanding of what exactly cured them. What if it was actually the radiotherapy they were given, or some combination of things they did or didn't do? And even if they did somehow know for certain what cured them, they're not me.

I went to an "Entheogenic Wellness" meeting and panel recently with Lisa S., Candradasa and Jessica. I frankly suspected they might be a bunch of drugged-up yahoos (I'm working on the cynicism, but apparently not very successfully). Some of it was about the interrelationship between human physiology and plants, and there was some science. However, there was nothing about treating physical disease.

P.S. My hair seems to be coming in at very different rates in different places, which is fine by me. Main things were the issues with my eyes and nose, which for the last few weeks have resolved. I remain without hair under my arms, which is fine.

December 7: **Uncool update**

I met with Dr M today. The nodules in my lungs appear to have grown significantly since the last scan. I have been getting (minor) chest pains, though I couldn't tell if it was simply emotions (the feeling in the chest is exactly the same.) Looking at the x-ray showed tumors where

I have been feeling pain. She asked me if I was open to doing more chemotherapy (keeping in mind that they will essentially have no idea whether it will work, and “working” doesn’t mean getting rid of the cancer, it means keeping things the same or maybe a bit smaller). I said the fact that there was no hope of chemotherapy curing it that is the biggest deterrent for me at the moment. I asked her how long she thought I’d be likely to live getting no further treatment. She said months to a few years, but the CT scan will give more specific info about size (how much it’s grown since the last scan) and also look for cancer in my liver which apparently is “another place cancer likes to go”.

All in all, not great news. I’m off to get a foot massage!

December 8: **Heartache**

After the meeting yesterday with Dr M and sad falafels with Tong, Jules and Candradasa, I went to the awesomely named Relax Feet for a massage. I had one coupon left that Kathy got me over the summer, but I forgot to bring it, but they only cost \$30 anyway. The lady badgered me into spending \$180 for three months. Ordinarily I won’t be badgered. But it was a great deal! And why not live a little?

While feeling the contact with my body and the slow relaxing, images and thoughts appeared. My mind went to my chest, how it hurts like grief, like a regular heartache, but is cancer. So finally it is heartache that will kill me. Again, I feel like no one, doctors, friends, me, was expecting it to go this way. But it keeps going. For the last few

months, the possibility that things might go in a different direction seems to get more and more remote. She said some cancers are resistant to treatment, like mine, and pancreatic. I didn't know mine had that reputation. Or maybe she was talking about mine in particular. An x-ray is a less specific and less toxic way than the other scans to get a feeling for how things are going. The nodules are obviously growing. The largest one in the left upper lobe is more than 42 mm (1.7 inches). Conceivably I could get two weeks of radiation before going to Hawaii (Dec. 27).

Recently I looked up the questions the SSF social worker advised me to ask the oncologists:

Do you foresee I'm always going to be on chemotherapy?

If I don't do more treatment, how long would I live?

Re more chemotherapy – What is it buying me? What if I don't do it?

What would a decline with my type of cancer look like?

I would add: What is the hoped for benefit of chemotherapy and what are the other possibilities? I wish I had asked Dr S that. I did ask Dr M #2. Next time I need to ask #4, although I think I know the answer – fatigue and shortness of breath, which I'm thinking must eventually lead to suffocation. Where else could it lead? Or maybe they have some way of helping one leave this world in a more pleasant manner.

Dr M suggested not being away for more than two weeks, primarily so they can deal with symptoms when they emerge. I feel very healthy and energetic (with minor chest pain and some radiation-reduced functionality in my pelvis). All the complementary medicine, walking, working with my mind, shamanic healing, eating no sugar... did it help anything? It makes me feel good anyway. I was thinking yesterday, My body is finishing up with living. The cancer is incredibly robust.

In any case I need to have a plan, so I'm planning to live for around another year. After that is just bonus points. Or maybe I'll start living on kale smoothies and that will cure everything, but it's hard for me to believe anything remotely like that anymore.

December 9: **Climbing Mount Everest**

I realized today that a big factor in the meeting with Dr M was her anxiety. She seemed truly alarmed by my x-ray.

I spent much of yesterday selecting books off my shelf to get rid of. Probably around 40 books. And a few more this morning. It was relaxing. Time alone on a project can be very nourishing. Sometimes I need a break from, among other things, other people's sadness.

What does it mean to "never give up hope"? That's the consistent cancer advice. Does it mean never give up hope that you'll be cured? But at what point does hope merge into denial? Maybe it simply means despair isn't good. I seem to have an extremely rare, probably incurable at this point in time, aggressive cancer. Is it separate from my body? Is it an accident, or wrong? Some Buddhist texts use the

word “adventitious”. Cancer could even be described as an “adventitious defilement” of the body. But the cancer is now part of my body. My body produced it. Can there ever really be an accident?

I was also thinking of the difference between thinking “as if” you’re going to die in a year, and planning one’s life around actually not being around in a year (or less). Apparently, neurologically, imagining something is almost the same as experiencing it. Yet, these two different varieties of imagination feel very different!

And what about living as if this day were your last? The idea is that you might do something radically different from what you were already doing. But what if it’s not like that? What if it’s not communing with the lemurs in Madagascar or climbing Mount Everest? What if what you wanted to do was walk around for a while somewhere nice?

What do I want to do (or not do) in the next year? Get rid of most of my stuff? Move to Oregon where they have a euthanasia law? How many retreats? I don’t know. The news has opened a box of questions about how I want to spend what remains of my life. The open box of questions feels very freeing in a way. No answers, so far. Emotions go to my chest in the same way they always have, it just hurts more now.

December 11: **Picking turnips with a step ladder**

I looked up euphemisms for death on you-can-be-funny.com. The title of this post is a fave. “Baste the formaldehyde turkey” – also charming.

'Top Five Regrets of the Dying' was written by an Australian nurse who spent several years working in palliative care, with patients in the last twelve weeks of their lives. "When questioned about any regrets they had or anything they would do differently," she says, "common themes surfaced again and again." To wit:

1. I wish I'd had the courage to live a life true to myself, not the life others expected of me.
2. I wish I hadn't worked so hard.
3. I wish I'd had the courage to express my feelings.
4. I wish I had stayed in touch with my friends.
5. I wish that I had let myself be happier.

I don't have any of those regrets. I suppose I regret not staying in touch with some people I've met over the years, traveling, etc., but I don't think that'd be at the top of my list. Let's see...

1. I wish in the fairly distant past I had preferred love interests based on kindness and humor rather than height and looks.
2. I wish I hadn't smoked cigarettes. (Probably unrelated to my current predicament, but still seems totally horrible from here.)
3. More recently, I wish I hadn't complained as much as I apparently did when I was director of the Buddhist Center. (Seems to be most of what some people remember about the eight years I was director, which makes me sad.)

That's all I can think of, though there are possibly myriad minor regrets. In any case, all of this was the best I could do at the time, and besides that, everyone makes mistakes, so why regret? But one does. I'll try to let it go before I get in the horizontal phone booth. (I find these expressions very funny, I hope you do, too.)

Currently I don't have an appointment to talk to Dr M, so I don't know what was found on the CT scan, though I have my suspicions. When I called, there were no appointments available. I sent her an email this morning asking about the results of the scan, and one to Dr O (radiation onc). Dr O replied that unless there was shortness of breath or pain coming from a very specific location, it wasn't worth destroying lung tissue with radiation. So I guess I'll wait to hear from Dr M.

I was thinking about Misha telling me last week that my 'upper burner' (basically, the heart) pulse was very weak. (This does not mean in western terms that my heart is weak. Not sure what it means actually, but obviously she noted some kind of serious vitality issue in my chest.) I have a consultation with Misha tomorrow.

Talking to any of my sisters is totally fucking sad, as are many other interactions. That's the way it is now and for the foreseeable future.

I came here (Cafe La Boheme) to write, but much of what I've done so far is look up physician-assisted suicide, euphemisms for death, and answer some emails. I feel confused, though writing this felt good.

December 13: **What hope in this context means**

Yesterday: Breakfast and meditation with Karunadevi, Skype call with Trebor in Berlin, a gentle Iyengar class which felt good on my sore hips, and an hour meeting with Misha... and watching Homeland (second to last episode), and the movie Ted. The main thing I took away from the meeting with Misha was that she was hopeful or at least suggesting the possibility that we could find some kind of treatment (not necessarily chemo) that might prolong my life.

Apparently my health plan will pay for treatment if they can't provide it. Misha suggested that I convince my doctor that I need to go to UCSF, which has a gynecological cancer clinic and does experimental treatments. I also need to call Dr A and The Second Opinion folks again. I realized that the hope that everyone says you must hang on to when you have cancer is... well, I suppose the opposite of 'I'm not going to do anything proactive anymore, just going to wait to die, which should be soon.' Perhaps that attitude is appropriate at some point, but not when one is feeling healthy like I am. It reminds me of the idea of 'learned helplessness' which wikipedia defines as "the condition of a human or animal that has learned to behave helplessly, failing to respond even though there are opportunities for it to help itself by avoiding unpleasant circumstances or by gaining positive rewards. Learned helplessness theory is the view that clinical depression and related mental illnesses may result from a perceived absence of control over the outcome of a situation." Still, I can't say what the hope is for. Perhaps one can remain proactive while dying.

It also occurred to me that I could start some kind of chemo, and stop when I felt like it wasn't worth it anymore. I had been thinking of it as 18 weeks of chemo or zilch, but there might be something between...

I just heard from Dr M:

Ms. Cullen –

I have attached a copy of your CT scan report. There has been progression of the disease in your lungs and you also have some lymph nodes in the middle of your chest. None of the findings are “pressing” on any structures that warrant proceeding with radiation right now, but I do wonder if the “ache” is related to the progression. There is no cancer apparent in your liver, adrenal glands or other areas. The bone findings are harder to interpret, as the sclerosis mentioned on the report, can be from bone healing.

It is always hard to predict how a person will do, particularly someone as young and otherwise healthy as you, and with you looking as good as you do right now. I, though, suspect that over time you will become weaker and that cough/shortness of breath could be issues. If you do not do chemotherapy, or do not respond to chemotherapy, you may benefit from radiation. Your pace of disease, though, does worry me as there has been significant progression over a relatively short period of time. Thus, I am concerned that survival will likely be measured in months to maybe a year. But, please to not start a “count down”

as this is just a suspicion. As time goes on and we work together I will certainly be honest with you as to what I am seeing. Also, I think you will be able to judge what is going on and have a good sense of when time is becoming much more limited.

Yesterday, Misha and I talked a bit about alternative treatments and how quack-ish they can seem. I complained that people don't give realistic info about what they can do. She said she figured the reason they don't is that many people won't go to you unless you say you can cure them. For example, she doesn't tell Hep C patients that she can cure them, so they go to another acupuncturist who says they can take away the virus. Anyway, Misha thinks it's worth looking around for options, trials and second opinions. But the folks at thesecondopinion.org can't help. They say: "We just don't have docs that deal much with cutting edge treatment or clinical trials... would be a waste of your time." They recommended some doctors at UCSF and Stanford who I could consult.

December 15: **Needs**

The other day I had a session with B, the palliative care social worker. The theme that eventually emerged was 'needs'. I'm not used to having needs, or at least I'm not used to expressing them. I'm used to being 'fine'. Part of my experience then is just letting needs be there, mine and other people's, and letting mine be known when that is helpful. They don't have to be the same and they don't have to be in conflict. It's all super basic, but new to me in the situation I now find

myself in, navigating this mysterious process I'm going through, and that other people are going through in relation to me.

Since the meeting with Dr M last my days are full, vivid, a roller coaster ride of contentment and sorrow. Again, I am adjusting to my current situation. I often wake up feeling happy, and my time with people is very sweet and poignant, no matter what is being said.

There are lots of things – well, it's been greatly reduced so let's say a few things – I would like to do. I don't know how long I will be alive enough to do them. Paramananda suggested that I do the things I want to do and not worry about whether I have enough time to do them, which sounds good. My priorities are to ordain Dawn and spend time with her, and to produce a memoir of the last year/this blog. Getting rid of a bunch of stuff would also be grand. Of course I will be spending a lot of time with other people besides Dawn, too. BTW, not going to Hawaii anymore. I'm meeting Cull in Bali on December 25.

December 17: **Canceling everything**

The last several days I have been feeling happy. In a way, I probably have less to worry about than you do! Almost all the 2013 travel plans I made, I have canceled. After I get back from Bali in mid-January, I'll be focusing on Dawn's ordination for at least a month. Very happy about this. If I am able I may go to New Orleans week of March 24 with my sisters, Julie, and Jeff. Paramananda may be coming out in early April.

Misha is going to make me an herb formula, don't know if she'll get to it before I leave. She's going to have it pre-made so I don't have to boil mountains of nasty leaves and bark, etc. I'm looking forward to being warm for a few weeks. Thinking about getting a small tattoo in Bali – over my heart. Words or a picture. (Jayarava's post, A Real Buddhist Tattoo, put me off the idea of using Sanskrit words!)

Here's a poem by Buddhist friend Leslie (McCormick) in Colorado:

It's Not Funny

She faces the words stage 4 with a shiny red nose,
clown shoes on, and dukes up.

Cancer may win her body,
but she'll be damned if she lets it take
the shoes.

December 18: **Benefits of cancer II**

1. People (mostly, but not only, my family) give me money or want to give me money.
2. I can do whatever, and no one gets mad at me.
3. I hear, and say, "I love you" approximately 25x more often than I used to.

December 19: **The profound lesson of reception**

Jim, from the Gay Buddhist Fellowship, was a delightful lunch companion at Osha Thai the other day. He is a hypnotherapist. Of

course he helps a lot of people quit smoking, etc., but he has also worked with people who are dying and afraid. I asked him what he does with them. Not sure how he does it of course, but he somehow shows them how to separate their consciousness from their body (so that they can see their body from above). He helps them have an experience of themselves that is different or apart from their bodies. He said they're less afraid after this, or not afraid at all.

My first thought about this was, Oh yeah, convince someone that there is life after death and they lose the anxiety, because they then think that they will keep on living. But there's more to it than that. I think it's more that we have solidified (or in the excellent words of the SF county jail: thingified) things-as-they-are-now to a degree that we are cut off from a different perspective, that there could be some other kind of reality. We can't imagine there is anything outside the box we are sitting in, so we cling to the walls of our box. (A favorite Chinese proverb: The frog in the well cannot speak of the sea...)

The same day Jayacitta (in London) and I talked on the phone about relaxing around the grasping or 'reality'-creating mind. The way she talked about meditation made me feel like we were working with exactly the same things. The main difference is that when I try to know things that can't be known, or cling to some form to which I want to stay affixed, it is way more painful these days than it was before I had cancer. I'm very much trying, and sometimes able, to accept things as they are, and not with resignation but with creativity and love. I referred to this once in a talk I gave as 'the complete embrace'.

I don't see death as a stopping of everything, but as a big change. To see it as a final end sounds kind of crazy to me. (But then again, who the hell knows?) Since I was a child I have had a strong sense of having been around a long time. I have a sense of having done all the sorts of things that both men and women do, many, many times. And I don't just go around saying that, because many people think you're bonkers when you say it (even other western Buddhists!) or that it's just some fantasy you constructed to quell your fear of the truth. But it doesn't make me feel better. It's not even a belief. Intuitively and deeply, in light of my own experience, it simply seems more plausible to me than other scenarios. As if everything that happens in our brain can't be taken at face value unless science has proved it. My mind has been around, in one form or another, longer than science.

I find it astonishing how not-sad I am lately. It's important that I don't expect that of myself all the time, but dammit, I am enjoying it. I also feel very healthy, very much alive. Out with a bang not a whimper I suppose.

You road I enter upon and look around, I believe you are not all
that is here;

I believe that much unseen is also here.

Here the profound lesson of reception, nor preference nor denial.

Walt Whitman, from Song of the Open Road

December 20: **Just the facts, Ma'am**

Lisa Kee, Padmatara, Julie and I met with Dr M today. The best case outcomes for chemotherapy: The ideal is that there are symptoms and the chemotherapy relieves them by shrinking the cancer. If there are currently no symptoms, chemotherapy would delay the symptoms developing. She said she didn't think chemotherapy was worth it if it only slows progression. I might try it, until it starts to suck, I don't know. She can give me ones that are known to be better tolerated. They won't necessarily work any worse than anything else!

I have written to Dr A asking the potential benefits of consulting with them (since my insurance won't cover being treated by them, and Dr M doesn't think it's a good idea to get treatment in a place I don't know anyone). Median metastatic survival time is 9-12 months. I don't really know what those stats apply to. Overall cancer? My kind of cancer with or without treatment? And I forget what median means... It's been six weeks since we first found out about the nodules. The only part of the meeting that was intense for me was asking if I would eventually suffocate. She said morphine works well for dealing with shortness of breath. I will talk to the social worker about hospice care. Signs of nearing the end include getting weaker and fatigued. Dr M said I will know when time is getting short.

December 21: **Brick shithouse**

Watched the rest of Little Big Man tonight. For such a silly movie it does get really sad. Then an hour of David Attenborough's Madagascar. Wonderful. I have been breaking my three things a day rule. Every day. And sleeping a couple of hours less than I usually do,

but it seems fine. Not doing a lot of napping either. I have the energy for it, I guess. My eyes have gotten really crap in the last few days. I can't see anything unless it's pretty much across the street (where, by the way, Tong and I saw a raccoon recently). I wish I could get more suitable glasses before leaving town. I can hardly read what's on my phone.

I won't be available much until after Dawn's public ordination on Feb 9. However, if you are thinking about visiting or have some other question for me, please contact me directly. You will know by reading this blog when I am weak and having a hard time breathing – that will be a different matter. For now, please remember this very important and up-to-the-minute fact: I am alive, and still built like a brick shithouse.

December 22: **The demon alcohol**

I haven't felt well, possibly because I drank a glass of wine last Friday. I sometimes get ill a few days after I drink alcohol (no matter how little or what kind). Gravelly voice, my mouth totally parched, very thirsty, and completely knackered. I slept until 2pm and feel better. Might be time to get back to my three-things-a-day rule. I haven't been resting enough.

Many errands yesterday. Got my eyebrows – they were starting to resemble caterpillars – waxed, which was astonishingly painful. Tried to get my car looked at (emissions light on but not blinking, probably not a big deal). Also went to my health plan to get my records

forwarded to Dr A in Chicago. I figure if I do a phone consultation with him, I'll want to do it soon after I get back from Bali.

I don't know where the line is between realistic optimism and chasing down snake oil. Or, put another way, accepting death without being resigned to it. Where is the point at which a plummeting quality of life becomes not worth living? At what point does the search for medicine become a distraction? I have no answers.

I know I'm supposed to be optimistic, but I am not. I also do not believe it changes anything. After all, when I was first diagnosed, I was not hopeful, and yet I had a complete response to treatment. Then I was pretty optimistic when the lung mets were found, but that ended up being groundless. However, should everything change, that would be fine. I can't bring myself to count on it. It's better for me to prepare for death, then all the life and love that happens is a bonus.

December 24: **Disarming bombs vs bodily scans**

Watched Frankenweenie and The Hurt Locker recently. Both featured themes of death and love. One between a boy and his dog, and the other between a man and something about the act of defusing bombs. Interesting the different ways one may face one's mortality. My way lately has been relatively abstract: mostly impressions on a screen.

I am enjoying being alone in my apartment since Saturday. Spent hours last night on the 17-page questionnaire for a potential phone consultation with Dr A in Chicago. (I answered all the questions, but

wonder why he cares what kind of dental floss I use!) It's shocking how much my eyesight has deteriorated in the last two weeks. I will need to get glasses when I get back. I find getting ready to travel overwhelming. I always have, but it's worse now because I have so much sick person gear to bring with me. That's why I'm writing this instead of packing. In any case, leaving for Bali tomorrow. Where is my passport?

December 27: **The End of Your Life Book Club**

'Eat, Pray, Love' notwithstanding, and in spite of having been here before, I had forgotten what a spiritual, healing sort of place Bali is. And how beautiful it is, that there is art everywhere, and little offerings, on doorsteps, and sculptures and "family temples". Had an excellent lunch or dinner or breakfast, whatever it was, yesterday. It involved fresh spring rolls, tofu with peanut sauce... I don't think there will be any problem getting healthy vegetarian food here. Last night I had a coconut, lime, mint, and lichee juice. They don't add sugar to the fruit juice, yay!

Cull brought me 'The End of Your Life Book Club' by Will Schwalbe. Here's something I was struck by (while wide awake at around 4am this morning): "Everything would be all right, everything would be possible, anything could be salvaged or averted, as long as we all kept running around." He quotes 'The Etiquette of Illness' by Susan Halpern. His version of the advice from that book:

1. Ask: Do you want to talk about how you're feeling.

2. Don't ask if there's anything you can do. Suggest things, or if it's not intrusive, just do them.

3. You don't have to talk all the time. Sometimes just being there is enough.

His mom had pancreatic cancer.

I'm sitting on our porch in front of a super green garden. It is overcast, the hum of insects is constant. A fly is walking around this screen. Roosters crow all night. We're telling ourselves we should go out now (9am) before it gets too hot, but we're still sitting here...

December 29: **Cremation parade**

Kadek, the lady who cleans our room here and shows us around, invited us to a cremation. Really? You just invite random people to a cremation? Needless to say, the attitude toward death here seems to be amazingly different. The event itself wasn't so much a cremation – at least not what I think of as a cremation – as a series of rituals that include a huge party, a parade and a cremation, and maybe things after that, but that's how long we stayed.

We waited around for hours in the boiling heat for the procession to start. When explaining the communal aspect, she said, "Some day I am going to die, and I will need people to help." Then it rained buckets and the air cooled down quite a lot. We had a big umbrella, and random folks would just come and stand under it. Of course they would, why not, except people in the west wouldn't do that. There

was a huge bright red lion (with astonishingly realistic genitalia!) around 25 feet tall, standing on a bamboo grid that was used to carry it, and hundreds of people, some musicians, some on motorcycles, most walking, some carrying offerings. After walking for a while we ended up in a park where the huge lion was put under an awning; then a big pipe full of gas was shot at the lion and it all went up in flames. The whole event made me think of how much more 'relational' other cultures are, how you sit around chatting all day, which is lovely, though I personally find it kind of exhausting!

On an unrelated note, suddenly I have an astonishing amount of hair (white hair, but still) on the side of my face. Given the right light my sideburns could easily be mistaken for Hugh Jackman's AKA Wolverine's in The Avengers. It could be that my hair is growing back weird after chemo, or maybe it's just one of the many perks of my newfound membership in the middle-aged lady club.

Kathy and I went to a lovely spa yesterday. We were talking about acceptance. I was saying the only thing I have a hard time accepting is certain physical changes I feel like I'm "too young" to have. As I have mentioned before, some physical problems I have are shared by many people (older, my age, and younger) who are just dealing with them anyway. I am simply not used to having physical problems so I imagine them to be more of a hardship than they are. Like every once in a while I bash my foot on something... or I'm sitting on my bed and can't lean forward far enough to reach something that is actually rather close... all in all, not a big deal.

I wanted to add a thought to the three tips from The Etiquette of Illness I posted last time. I post things like that because I find them interesting, then after I post them I think, The people who have done the things advised against in that list, do they think I am chastising them in some way, or upset when they ask me if they can do something? If you thought that when you read that list, perhaps you need not worry so much about saying the wrong thing.

*

Tolerance

21 September 2008

I got really annoyed with someone yesterday. Fortunately I had a chance to reflect a bit afterwards, and I got to thinking about standards. I was wondering whether everyone has a list – an unconscious list – of all the things “a person just shouldn’t do”. A lot of things on the list have to do with sharing space, which is why living communally can be so difficult. Items on the list also include prohibitions to do with time, hospitality, ethics, work, friendships.

What’s one of the items on your list?

The world hosts all kinds of people, including people who aren’t going to be able to contribute much, including people who not only aren’t going to contribute much, but who may only bring their own needs to a situation. People who might even criticize you for what you are contributing, or for not going out of your way to meet their needs. The world includes all kinds of people, who are ‘created equal’ in a certain sense. But being equal refers to rights, or even potential, but it doesn’t mean everyone can contribute equally to a situation. They cannot. Some people will give, some people will take, some people won’t do much of anything. Confusion about what’s fair and what’s right gets mixed up with this basic situation, that the world includes all kinds of people.

So, the list of “how people should be” has to be overcome. It is too narrow for us. Believing the list is like not having good eyesight and

walking around without glasses bumping into things, some of which are spiky. If we put on our glasses we see that things aren't attacking us. It's that we are attached to them; our standards pull them toward us like a magnet, to switch metaphors. This is why we cultivate kindness, to stop punishing ourselves. When we practice kindness and tolerance we desist from picking up the proverbial hot coal with our bare hand. In this virtual metaphor smorgasbord, I say, finally, that to do this - to cultivate tolerance and love - is a lot of work, and is the final frontier.

January 25th: Getting ready to go on retreat: the robes really go with the post-chemo do, yes?
Never mind the sideburns.



January 2013: Everything Looks Beautiful

January 1: **Mongoose poo**

Being in Mexico and now being here in Bali has made me remember how awkward it is for me to suddenly be rich relative to most of everyone else. At the big Hindu temple in Sidemen (SEE duh men) the other day, a seemingly endless stream of excruciatingly cute little girls would ask us very sweetly to buy postcards. Men standing around Ubud, where we are now, say TAXI? when you walk by. In touristy places anyway, one becomes objectified, a bag of money, or that's how it feels. I'm not saying it doesn't make sense, or that it's a huge hardship, just that it makes me feel bad, especially when I feel irritated by the persistence of gorgeous children. I'm much more comfortable being the poor one.

I've been feeling energetic and healthy, except in certain kinds of light when I can see all the blond wolverine fur on my face. That's a shocker. But the minor chest pain that I had seems to have gone away. I felt it again when I drank some super gourmet coffee at a luwak coffee plantation the other day. By the way, luwak kopi is essentially mongoose poo. Seriously: A mongoose type animal, locally called a luwak, eats the coffee berries. Their shit is collected, cleaned and brewed. We saw a sad restless luwak in a cage, but mostly they just collect it from the forest floor. Apparently you can buy a cup in

London for £70. But the original point was that it seems that drinking coffee of any kind makes my chest hurt. I'm so done with that.

Also, Cull has some kind of Bali Belly at the moment, poor thing! She's been in bed since yesterday afternoon. I'm heading down to a restaurant in town, Casa Luna, to meet Kiranada, a friend who comes every year from New Hampshire. Then we're headed to Changgu which is in the west and I think at the beach.

January 2: **It's raining in Seminyak**

I forgot to say: The luwak coffee was good. And to clarify, the coffee is not technically shit, it's the whole beans after having been partly digested by the luwak.

It's the rainy season now, or one of them. The first couple of days, it would rain for an hour in the afternoons. Now it seems to be raining all the time. Part of where we're staying is outside (a roof but no walls, it is very swank). I walked out of my bedroom this morning into a deluge.

Kathy has recovered from Bali Belly. We are in a very different town now, Seminyak. Walking isn't much of an option, especially in the pouring rain. Balinese people seem to be consistently lovely. Tonight I'll hopefully be making soup with some special white mushrooms ("Highland white fungus") Cull brought from Singapore. They're supposed to be good for lungs (her lungs are messed up too though in a different way). I seem to be forgetting about cancer, which is handy.

January 3: **End**

Ratnadevi sent me a link to [Julia Darling's website](#). She was a writer who died of cancer. Here is a great poem from her blog:

End

Eventually, I was placed on a bed like a boat
in an empty room with sky filled windows,
with azure blue pillows, the leopard-like quilt.

It was English tea time, with the kind of light
that electrifies the ordinary. It had just stopped raining.
Beads of water on glass glittered like secrets.

In another room they were baking, mulling wine.
I was warm with cloves, melting butter, demerara,
and wearing your pyjamas. My felt slippers

waited on the floor. Then the door opened
soundlessly, and I climbed out of bed.

It was like slipping onto the back of a horse,

and the room folded in, like a pop up story
then the house, and the Vale. Even the songs
and prayers tidied themselves into grooves

and the impossible hospital lay down its chimneys
its sluices, tired doctors, and waiting room chairs.

And I came here. It was easy to leave.

January 5: **Easy rider (not)**

On Friday after a dream in which I was in jail because one of the jailers didn't like me, I felt sapped of energy and slept much of the day. I felt better the next day.

We got a motorcycle, it's really the only way to get around. More of a scooter. Driving around in the torrential rain, relatively chaotic traffic, navigation, and (for me) switching sides of the road, was rather nerve-racking, though it was cool to be able to get where we wanted to go without a taxi. (I guess!) I drove for the first minute and once I had to merge into traffic, I stopped and Cull drove. We had a good Japanese lunch and wandered around, did some shopping at Supermarket Bintang, got \$9 massages (1 hour.) Also Kathy bought a bracelet that is either silver, or "silver," we're not sure.

The soup we made with white fungus (reputedly good for lungs) was foul. She thinks it's because of the fungus; I thought it was because of the veg broth I made. In general I still have a fair amount of energy, but my lungs feel congested and I've been coughing a bit. Was wondering if they're irritated by the air conditioning... or if it's the other thing.

January 8: **The destroyer and the creator**

Seems like what an oncologist is always looking at is how much chemotherapy might prolong your life vs. how much of you it will destroy. It adds time and takes away functionality (though it has improved a great deal over the years). I started thinking about this when I was reading The End of Your Life Book Club, in which the guy

takes his mom to chemo and they talk about books. She had pancreatic cancer and lived around 18 months (much longer than she would have, probably, without the chemo). During that time she did a lot of things. She also spent much of it inconvenienced at best, and at worst, miserable. She stayed alive as long as she could.

I sorta feel that I want to take care of myself in other ways and let nature take its course. But I can't really say that until I am responding to a specific proposal. A while ago Dr M was talking about chemotherapy as if it might add a few months to my life. She is going to consult with Dr C at UCSF before we meet on January 15, at which time I guess I'll find out what chemotherapy she's going to suggest. (She won't suggest actually starting anything until I start having symptoms.) She will not be surprised if I refuse more treatment, since, at least based on what she's told me before, what's on offer will more reliably take away functionality than add time.

But saying I want to do what is 'natural' doesn't quite get to it either. I don't always choose 'natural'. My life, and probably yours, revolves around tasks, buildings, modes of transportation, and technology that are artificial, man-made, fabricated. I realized the thing I want to avoid feeling is 'force'. I don't want to feel like I'm forcing my body to live.

Still, all my records have been sent to Dr A in Chicago and I have written to them asking if I can do a phone consultation with them the week I am back. Also, Nancy found a contact for me at UCSF clinical trials who I'll hopefully be talking to in February.

I don't want to complain, but I don't want to be vague either. This is a lovely place, and I am enjoying it. I think it's hard for people to get this when we aren't together in person: So far I do not feel sick, and I do not look sick. If you saw me the only difference you would notice is that my hair is very short. I have been described as "full of life" – that has not changed.

January 10: **Such is the perfect person. Her boat is empty.**

I have minor physical complaints which are the result of my body aging I think 10-15 years as a result of cancer treatment. I am not in pain. Apparently there are rapidly multiplying cancer cells in my lungs. I cannot feel them, nor do I have shortness of breath. I've been coughing some. I'm pretty sure it's from the super dry air conditioning in the room I sleep in although I seem to be getting used to it. I turn it off the rest of the day which I wasn't doing before.

The way my hair is growing back after chemo is surprising. The hair on my head is still very short, and way grayer. Eyebrows are back in their full glory. And as I may have mentioned before, I have very fine (in the sense of awesome, and in the sense of subtle and perceived with some difficulty) blond hair growing where men have sideburns. On the left side of my face the hair points straight down. On the right there is less and it sways in toward my nose, like a wolf. Or, perhaps, a superhero wolverine. Hello, Hugh Jackman.

The main point I wanted to make is that even though I seem to have one foot firmly planted in the grave, I don't currently feel sick. Another

cancer change, again relatively minor, is that I'm much pickier than I used to be about food. I used to be more flexible, more working class. Now I take four anti-inflammatory pills and various other supplements every day. I try with varying degrees of effort to avoid white flour. I eat almost nothing with added sugar, occasionally some dark chocolate or a bite of something. I don't really miss it though it's a pain reading ingredients, especially now that my eyes don't work as well (unrelated to cancer, I think) and there seems to be sugar in almost everything. Avoiding it for so long, most of the time I don't desire it anymore.

I was pondering the other day how lovely and nice and sweet the people in my life are. I mean I wouldn't have said that before I got cancer, not 'cuz I thought they were bastards, but of course because things have changed. No one tells me what they think I should do, unless I ask. It is lovely.

I was reading Stephen Levine's *Who Dies?* last night. There's this great part about being an empty boat, a Taoist image. I don't know if that's enough of an explanation, but I find it an inspiring idea. As an example of not being an empty boat... There is a sort of touchy issue for me, it doesn't come up very often but it does come up. It's when my mind goes to thinking people are acting as if I'm already dead or, even, too sick to do something (when I do not feel sick at all). It's just someone doing something nice for me or taking something off my hands, and I think, Good god man, I am not dead yet! Then I sort of get over it and realize they are trying to be kind. It's a process. Perhaps from the point of view of the full boat, there's always going to be the right kind or the

wrong kind of kindness. Most of the time I am very, very happy with my circumstances. Vimalasara suggested I have a living funeral. It sounds groovy though I don't really know what it is.

I'm writing two poems: Mind on Cancer, and On the Occasion of my Seventh Balinese Massage. I can't really finish poems these days for some reason but I will try... I have a lot of appointments set up for the ten days I'm going to be at home before going on retreat with Dawn. The social worker, Dr M, three phone appointments with Dr A's office in Chicago, and on Feb 11, the clinical trials lady at UCSF that Nancy set up for me. And it's going to be cold and rainy, and there won't be any mangosteens.

January 13: **Everything looked beautiful**

Padmatara picked me up from the airport Friday afternoon. Everything looked beautiful. One of those clear afternoons with this kind of orange light shining on everything... even from the plane, the light, the tops of the clouds were beautiful.

We watched Extremely Loud and Incredibly Close (didn't like it that much, needed more editing), had half a Jay's seitan cheesesteak and went to bed at ten. At around noon when I woke up briefly I thought, Wow, that's a lot of sleep, but... maybe... just... one... more... hour... My joints were sore and my guts were painful. I finally managed to extract myself from bed at 10 am after an impressive 36 hours in bed. I don't feel too bad now, just a bit weak. Food poisoning combined with jet lag?

In any case, enjoyed Dawn's send-off this afternoon: Sevenfold Puja with 'rejoicings in merit', then offerings of a poem and a song which were both great, and 'cream tea', which I should point out for Americans means scones with clotted cream and jam. Dawn will leave for her retreat on Monday.

Back in bed, yay! The cold hasn't bothered me like I thought it would. I like it.

January 14: **The beholder's eye**

As to me I know of nothing else but miracles.

Walt Whitman

My days filling up and I'm hella jetlagged and coughing a lot today. It's 7:30pm and I will try to stay awake long enough to do this. It's nice not having ants crawling on my computer screen.

Talked to the social worker – about travels, a Living Funeral, my Advance Health Care Directive (I'm going to do a new one). Then walked at Ocean Beach. It was beautiful and sunny, and there were very cute little birds. If I were naming them I would call them Running Fat Cutebirds. I am as enamored with San Francisco as I was with Bali. Fact: Here is an astonishing lack of traffic. Look at the beach on a Monday, hardly anyone there!

I'm wondering about doing a Celebration of Life or a Living Wake or whatever when Paramananda is here in early April. I had asked him to

officiate at my funeral but perhaps it makes more sense to do it while he's here anyway and I'm still alive! I also looked up some places for cremations and natural burials.

Everything looks really beautiful. Is it in my eyes? Is it the light? Am I dead?

January 16: **Tsunami brain**

Apparently the birds at the beach are called piping plovers. Potential problem with Living Funeral/Celebration of Life: Zero idea of what I would want to do, or be done.

Talked to Dr M with Jules and Padmatara. She (M) must have had a nice holiday herself as she seemed much more relaxed than usual. I get the feeling, and this doesn't mean anything perhaps, because it is a guess at what someone else is thinking, that she is about as enthused as I am about me doing more chemo. Perhaps even less so. She mentioned a patient who was dying of liver cancer and refused more chemo, and went into complete remission from taking some kind of mushroom.

On the other hand, she says when I start developing symptoms I should start treatment quickly. At the moment my lungs sound very healthy. Healthy people are much more likely to tolerate and benefit from treatment. I said mid-Feb is the earliest I could start and she thought that was reasonable. She seems to be leaning toward a drug called CPT-11 possibly with Cetuximab (geez, who are the crackheads who come up with the drug names?) She said we would know within

six weeks if the drug is working. (My thinking is, I can maybe deal for six weeks.)

I got an x-ray and will hear from her on Thursday how it looks. My fantasies tell me that the nodules [Q: What is the difference between a nodule and a tumor? A: A nodule is smaller.] have stopped growing, 'cuz that would give me a break from the vague sense of my-lungs-as-time-bomb and, more than that, relieve me of having to make the decision whether or not to do more chemo. But they probably haven't. They're probably growing like gangbusters (a phrase my dad used to use). My cough (which has gotten much better) apparently isn't a cancer cough, which is lower, persistent, and may include blood. If I do more chemo, domestic travel for two weeks or less is reasonable.

We're still waiting on results for the "EGFR mutation." If you are in need of a mnemonic device to remember that, some of you will be helped by thinking of "Effective Going for Refuge mutation." If it comes out positive, she will want to try Tarceva, which is effective 80-85% of the time for EGFR mutation positive primary lung cancer patients (keeping in mind that I am not a lung cancer patient!) I like the sound of this drug because it's a pill, it's "well tolerated" and I believe I heard that it doesn't cause hair loss. So I vote for EGFR mutation positive, and Tarceva.

I am feeling overwhelmed with things to do. My calendar (for the next week or so) is filling up fast. But today because I did not go to Art for Recovery and Mike canceled dinner (he's sick), I get to putter around

doing stuff, changing sheets, laundry, lots of emails and calls and I try to meditate while I am doing them, so I'm feeling a little calmer.

January 18: **Senior citizen pelvis**

Last night when I went outside to move my car I could only open the door about six inches. The dent next to the driver's side door is hardly even noticeable... all I have to do is get in on the passenger side. Not that easy for a senior citizen pelvis. Plus if I drive into a lake it's curtains.

Saw Misha today and she gave me a big bottle of foul and nasty liquid to add to water and drink four times per day. Around 8,500 steps, a record in recent history.

If I do the Living Funeral/Death Party, it is likely to be April 20 or 21. On the fence about it now, but currently frying other fish, to mix metaphors. I have to think about whether I am really motivated to do it and what the reasons would be. Candradasa sent me a link to getyourshittogether.org (Life and Death Planning). They even have a checklist, which is awesome. I might have waited a bit too long to think about doing this stuff.

January 20: **How much money for some life?**

I'll have to narrow down the focus here to the talk with the oncologist Dr A. First thing I noticed was that he didn't talk like other oncologists I've spoken to. He sounded like a regular person. The way they do chemotherapy at his clinic is called "chronotherapy" – it's administered somehow in line with circadian rhythms and reduces side-effects by

40-80%, he says. They treat peripheral neuropathy with cold lasers. He knows of clinics in Israel, Cabo (Mexico), Germany, and Korea doing experimental therapies. If I had \$100-200K to spend on it that'd be groovy. He did mention a few drugs to look into – Anvirzel, an extract of oleander that you can only get in Honduras, and the diabetes drug Metformin, which has done very well for diabetics with ovarian cancer.

How can I think of my life in terms of how much money it's worth? Curing my condition would be worth a lot! I'd pay it back! But no one thinks that's going to happen. Is adding a possible one or three years to my life worth \$100 or \$200K? Never mind whether I could get my hands on that much money. Asking the question depresses me. Perhaps there is a different question I should ask. (Or, better, forget about the whole thing!)

The second bummer thing, though not surprising, was the answer to my question about whether there could be effective alternatives to chemotherapy – tomato enzymes or seaweed fungus, or whatever. He said my cancer is too far gone, I'd need some kind of chemotherapy.

He's going to get back to me about various things, and of course I have other irons in the fire. I haven't heard back from Dr M yet, and I still have the other consult at UCSF in Feb. I was thinking today though that even though my pelvis is messed up in multiple ways that make me feel old, at least the radiation got rid of all the cancer there.

So that was worth it! Right now, I don't want to talk to any more doctors.

January 21: **Meditation and gun jumping**

I was thinking about how people who can accept a big learning curve for many types of new tasks seem to make an exception about meditation as something they simply won't be well suited to or can't do. I thought this while listening to a talk about meditation as a learning experience by Gil Fronsdal. It's a good talk.

I sorta jumped the gun on the Living Funeral thing because Paramananda is going to be here in April. Realized it makes no sense to me to plan that kind of thing now... I'll be up in Lake County at Dawn's ordination retreat on Thursday or Friday for about two weeks.

January 25: **The accountant and the preceptor**

The accountant in me – or the biographer – wants to record things whether or not I have time to write about them in any detail. Like talking to the nutritionist for an hour, and attending my final Board meeting for the SF Buddhist Center, officially resigning and finally addressing some painful issues that have been kind of hanging over the thing since my last meeting over a year ago. Suffice it to say: something of a relief.

Re. the Center in Chicago, I think they are very innovative and want to help people, and also what they offer, including a whole range of supplements, seems to be astonishingly expensive. Is it better to buy their supplements? I don't know. I opted for Sears and Vitacost. (If I'm

dead in a month we'll know why.) It did occur to me that they do phone consultations in order to sell people stuff. But I suppose if the stuff helps people, there's nothing wrong with it. I'm sure their expenses are substantial.

Viradhamma got the dent pulled out of my car for free so I can now open the door.

I got the results of my last x-ray last night. Seems like the nodules are not growing nearly as fast as they were on the previous scan. Looks like increase is 30% and 5%. (I'm assuming here that they list the nodules with the most growth.) Hard not think "this is how it will be from now on" but I'm learning a bit more not to think in that way. From my point of view, since I was diagnosed with Stage 4 cancer over a year ago, my situation completely changes every few months. Dr M also said she found out that the EGFR mutation test can't be done as there isn't enough tissue. She didn't think the results would give enough info to make it worth doing a biopsy.

I'm going on retreat this morning and will be gone for two weeks to be with and ordain the lovely she-who-is-currently-Dawn. I can't write much about that process because it involves elements that are super hush-hush. I am unlikely to post from there, unless I have to spend time at the cafe for some reason. I had a helpful chat with Sanghadevi, my preceptor, this morning, who suggested not having medical conversations during the retreat if possible, which I think is an

excellent idea. There is no great rush to know Dr M's chemo proposal during the retreat.

I am looking forward to many things about the retreat. One is that I will be able to more fully focus on the task at hand and not be holding so many threads. Though I do seem to cough a fair amount, I am very grateful that I still feel healthy. Way healthier in fact that I did, say, two years ago. Still, after April I have no plans. The calendar drops off like a coastal shelf.

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Cultivating the inner retreat

14 September 2008

Why go on retreat? On the last retreat this summer, we saw an absolutely beautiful double rainbow and turned around to see this gorgeous golden light filling the sky. It was magical. Most of the time however it's not magical, most of the time it's what might look like a big drag. You file here and file there like a Marine, and you sit in a cold room in the morning (not that early, we are not of the Early Rising School of Buddhism) focusing on your breath for example. From the point of view of the Average Joe, what we do doesn't sound very good, might even sound like some kind of punishment. Or just boring. For some it is very much an acquired taste.

Truth is, I love life when I am on retreat. Everything is perfect, even pain, even difficulty with someone, or painful emotions or physical feelings coming up during meditation. There is spaciousness around everything. Even being annoyed at something is amusing. No constant chatter. No advertising, no news, no external distractions (plenty of internal ones however). We live communally, cook communally, live simply. Everything is very simple. Food, meditation, a small job, a walk, sleep – that's all there is to do. People are beautiful, especially after a few days. Clear eyes, smile on the lips or tears in the eyes, simple, nothing to blame. Just a way to notice spontaneous kindnesses when there is literally nothing else to do. You can go down to the little water hole and count 36 rust-colored newts floating around like idiots. You can wonder whether they're newts or salamanders.

But getting home is another matter. Life floods in, fills one up to the gills, and further. The structure is gone. The happy, calm, receptive people are gone. Yummy vegetable-intensive meals no longer appear like clockwork; they are replaced in part by hastily prepared, solitary or greasy restaurant meals. The circus of American politics grinds on. People don't have time to reflect much, living from knee-jerk reaction to knee-jerk reaction. And I become more like those people; and to do so is painful. I get swept away with work. Not every time. Sometimes I can keep the retreat vibe going for quite a while. This time, I lasted a week or two. After that, I started getting wrapped up in work, skipping meditations, and feeling irritable and anxious.

I started wondering: are retreats really that great? Do they really prepare one for regular life, or are the ignoramuses correct who think they are an escape from life? Honestly, I never seriously entertained these questions. However, sometimes transitioning back from retreat is difficult, and the feeling of contentment does not seem at all transferable. I can't seem to immediately take up personal responsibility and match it up with ACTION. But I wish I could. I wish I could more often achieve "inner retreat" here in the city, and for longer. An inner retreat means being unified. It means fully connecting with the part of me that responds positively to a variety of situations, that simply does what needs to be done, rather than wishing it were otherwise. It means the conditions for retreat are inside my body, my connection with nature is inside myself, no matter where I am. Ah, a dream...

February 5: Hridayashri and me, the day after the private ordination.

Photo, Padmatara



February 2013: Hope and fear

February 2nd: **On retreat**

Identity seems to be fading a bit. I thought it might. Am I young or old? Sick or healthy? Weak or strong? Rich or poor? A meditator or not? Worthy or unworthy? Anxious or calm? Tolerant or irritable? These identities come into sharp relief as words that stop meaning anything. Who is my self? Where is my self? Who is the self that angsts, that narrates, that projects into the future? They don't feel like me. They feel like something happening.

Wow. All that meditating. Now let me think... I have been here seven full days. Including morning pujas and sitting meditations, I've meditated... 260 minutes a day. So 30 hours since I've been here. I had one rewarding meditative experience today, say for around half an hour or an hour. Is that a good reward, good odds? You can't even know for sure that anything like that is going to happen. You can meditate for years and it doesn't happen (potentially). Of course the rest of it was good. It's not like it was torture. If it were I couldn't spend 30 hours voluntarily doing it. It's a kind of being – or leaning in a direction of a kind of being – that is its own reward.

And in any case being able to drop, or rise above, the narrow confines of the way I usually experience myself for a few minutes is worth... whatever. It is the most subtly liberating yet undefinable experience. And when you're having it, it seems like... normal. The rest of your life,

plus those other 29 hours you were meditating, those are the hours that are weird, that don't make any sense.

If you thought about that, but you don't. You see through the conceptions of world and self for what they are: pain fantasies through which experience gets filtered. Every single possible metaphor has been used. The veil etc. Things as they really are. Nothing can convey an experience of mind and heart that are free, however temporarily, from delusion. Nothing to defend, destroy, protect, create, explain. Nothing, even, to understand.

But "astonishing" is an epithet concealing a logical trap. We're astonished, after all, by things that deviate from some well-known and universally acknowledged form, from an obviousness to which we've grown accustomed. But the point is, there is no such obvious world.

Wisława Szymborska

February 8: **Things I don't know**

The public ordination is tomorrow and I have much to do still. But this blog is my friend – as are whoever you are who is reading it – and I simply have to check in with you sometimes, even when it would seem more sensible to do something else!

We had a great time. It was exhausting, too, but not too bad! There was a lot of stillness and a lot of activity. Much planning goes into such a thing. Karunadevi, Padmatara and Danamaya appeared at some

point for a few days to help, each in different ways. It was lovely to have them there. Then the private ordination, a deeply moving, beautiful experience.

During the two weeks on retreat, there were some useful reflections on my life and death. I became aware of the degree to which I am living as if I don't have a future, having no plans after April, certainly none for next year. Sometimes this is sad for me, sometimes it's neutral. Sometimes it's kind of liberating, like there is space in my mind freed up that used to be packed out with ideas about the future.

I'm taking loads of supplements, some of those recommended by Dr A, and drinking Misha's gross potion four times a day. I still feel healthy. I guess I'm going to live longer than a few months. I was told "a few months to up to a year" on December 7. It's been two months since then, and while I do cough a lot, I do not otherwise feel sick. But the prognosis is a perpetually moving target. "I don't know" is much simpler and less jarring.

Turns out chanting makes me cough (more). I did plenty of coughing on the retreat, much more when I was tired. Something else I managed to stop speculating about was whether the cough is caused by cancer. A few weeks ago Dr M said it wasn't, but I've coughed a great deal since then. Again, kept landing on "I don't know" which felt so much freer than always having to have some kind of answer.

The retreat was, among many other important things, another cancer holiday, during which, relatively speaking, I hardly thought about

cancer and doctors and choices and chemo at all, which is very restful for my mind.

February 10: **Whew**

It is a very interesting process naming someone (especially in another language!) Yesterday at the public ordination, Dawn became Hridayashri. It means “Radiance of the Heart”. Laura and Jon were there, which was nice. It’s also interesting wearing robes. I like it. It feels simple. I don’t really know how to do it, so there are hazards. Like walking upstairs and tripping over them, or wrapping them so tight that I can’t sit on the floor! I had it pretty much figured out for the ceremony.

February 12: **Dr L on the roller coaster**

Yesterday, Nancy, Trebor and I talked to the director of early phase clinical trials at UCSF, Dr L. It’s hard to know what to say about it, partly because initially she was so intense, and not in a pleasant way. (Oncologists are amazingly stressed out. I would love to teach all my oncologists to meditate!) The operation also seemed rather disorganized. On a non-cancer related note: During the preliminary blood pressure tests etc, I found out I am an inch shorter than I used to be! Which totally bummed me out. I thought that was supposed to start when you’re around 70. Yoga! Yoga! Yoga!

And now, back to the malignant main event. Dr L was convinced that my cancer, while it may have been “rapidly growing” at one stage, can no longer be described in this way, because I still have no symptoms.

She said that the chemotherapy I did must have continued having the effect of slowing the growth. I am inclined to think that other things I was doing slowed the growth. Of course there no proof either way.

The canceling of my “rapid growth” status was encouraging, however, it was based to some degree on my recounting of scans from memory. There was some confusion, as they could not seem to decipher my medical records, they apparently did not get the report from the January x-ray, and I cannot necessarily remember correctly when I got what type of scan. Plus, Dr L appeared to despise x-rays. The experience would have been a lot more satisfying if before the meeting someone had checked in with me about what info they needed, or if I had proactively inquired.

So some of her assessment may be based on my faulty memory. But people with tumors in their lungs can go down quickly apparently. My oxygen absorption is 98%, same as it's been for the last year. I told her (from memory) how much the nodules had grown in the January scan and she said it doesn't even count as growth. (Only a 20%+ increase in size means anything.) She was also emphatic that you can't tell anything about the growth of nodules from x-rays.

I do not see any reason to do a clinical trial, unless someone can tell me it's likely to work better than anything else. Also, Phase 2 or 3 clinical trials are usually specific to certain types of cancer, which in effect eliminates me, and Dr M said there were practical disadvantages to having a rare type of cancer in a phase 1 trial. She

said something like, “You’d be likely to be randomized against nothing.” Have a vague sense of what that means, but it doesn’t sound good.

If/when it gets to the point where I’m choosing a chemotherapy, unless a drug for metastatic vaginal adenocarcinoma miraculously appears, I’m going to choose the one with the fewest potential debilitating side-effects, none of which will be neuropathy. I haven’t heard of any better criteria for choosing a chemotherapy in my particular case, since what might work seems to be anyone’s guess.

Dr M said she would do a new biopsy. One reason is that the genetic markers on the metastases can be different from those on the original tumor, which I didn’t know. (Lung biopsy carries a small risk – .5%? – of collapsing a lung. Danamaya says they can fix it!) I also couldn’t remember what the results of my tumor sequencing had been. Apparently that wasn’t in my records either. Nancy remembered that the original tumor is “HER2 negative” which is to do with hormone sensitivity. I didn’t remember “positive for EGFR immuno-histochemistry.” They can do tumor sequencing on 300 common mutations. Of course when I asked if the genetic info about each of the mutations is actually useful, she said no.

It is astonishing to me the amount of information someone with cancer, or anyway someone with a rare cancer, is expected to retain and analyze. Talking to oncologists is like a massive rapid-fire science brain dump in which they give mountains of often undigested

information and one is expected to make sense of it somehow. A friend of Trebor's who is an internist said ideally they would help you with the decisions, or ask how they can help with the decisions. He teaches at UCSF/SF General and works with palliative care and hospice and I'm sure is a wonderful communicator with patients and doctors.

She listened to my lungs and, like Dr M a month ago, said they sound clear and healthy. Her basic message after an hour and a half of talking about stuff was pretty much, You're healthy, get outta here. Come back when you can bring CT scan images over a six month period, and cancer symptoms to go with them!

By the end, she was very nice and friendly. It was very interesting getting a completely different point of view on my case; however, I don't imagine I will go back to her. Of course if I did go back to her I'd make sure all the ducks were in a row and she'd likely be much less surly. Fact is, no doctor has, or professes to have, "the answer". They have different personalities and approaches, but they all have roughly the same data.

In any case, it was good news. I am very cautious about getting back on the "everything is fine" and "everything is not fine" roller coaster. All information applies only to now and maybe the next month or two. But it seems at this point that I maybe have a bit more time than I thought.

February 15: **Layman's terms**

I talked to the medical assistant from Dr A's office. I had called them and asked when their recommendations would be rolling in... turns out Dr A thought that she was going to call me, and she thought Dr A would. She also thought I was planning on going to Chicago to get treated. Alack. Here are their chemo recommendations, short version: Their primary recommendation are drugs called Taxotere and Gemzar. I didn't think to ask about side-effects. I hope I never need to. The two drugs could also be supplemented with a targeted therapy – not chemo, it's an antibody that turns off a growth signal called VEGF – called Avastin. It's FDA approved for cervical cancer and some good info about it has come out just in the last few weeks.

I got a copy of Dr L's (UCSF) report from Misha, my acupuncturist. (She's in their system and they sent her a copy.) They also sent it to Dr M, my main oncologist. But not, of course, to me. It was good to read. A few things in it aren't true; as I mentioned, they are based on what I could recount from memory about scans. Some odd things in it too. Like under drug history, it says "whatever was available". I must have written that on the intake forms! That's not true either.

Misha thinks my cough might be do to with allergies, which kind of makes sense to me, as it comes with allergy-like fatigue and no other symptoms. She was also wondering about "black mold" since it seems to be worse in the morning. I'm not sure about that and unfortunately testing for it is super expensive. Should go to an allergist, or whatever that's called. Plus an optometrist, and... Co-leading a retreat with Karunadevi 'til Tuesday.

February 20: **Gratitude**

Life lasts but a few scratches of the claw in the sand.

Wisława Szymborska

I had a great time at the retreat this weekend. Friends came from Seattle, Hawaii, Missoula, New York and Canada, plus locals. Some of us have been doing this retreat for 20 years. I led the most excellent study group ever (I mean because of the people in it!) I felt an astonishing amount of gratitude. I thought of how many doctors' appointments Julie has gone to with me. One afternoon Dayamudra set me up with a few restorative yoga postures. Elaine swept my room at the end. I can't actually remember the other things I was thinking of but they were pouring from my heart; the sense of gratitude was enormous. Almost the whole time, well, many, many of the hours there, I felt intensely present, calm, happy, and grateful, and on the verge, or over the verge, of tears. To have the life that I have, to do what I do, to know the people that I know.

I'm working on a poem I started on Hridayashri's ordination retreat, "House on Fire," which I read during the final ritual.

Healthwise: On the retreat I crashed at around 8pm every night, as if an evil-doer had placed the old-at-8pm-you-will-turn-into-an-achey-old-lady hex on me. Cough is about the same. I have hacked up, twice, some small, very bright red, worm-shaped phlegm. According to an article from the ever-omniscient internet entitled 'Snot and

Mucus Decoded: The Meaning of Snot Colors', it could be a sign of bronchitis. The American Family Physician website says that the usual causes of blood in phlegm in adults are pneumonia, bronchitis and lung cancer.

As much as it pains me to think of talking to another doctor, I made an appointment with my GP for next week. He's actually a cool guy, he meditates. I haven't talked to him in a few years.

February 22: **Roller coaster awareness and a different doctor**

Thursday was a long, long day, so tired. It started at 10:30 at my health plan, a super helpful meeting with the palliative care social worker, B. One of the things we talked about was the shorter/longer life expectancy "roller coaster" and the fact that I want to get off of it. She suggested rather than trying to get off of it, trying to be aware of being on it. Very Buddhist advice I must say! We also talked about financial power of attorney, and the advance health directive. Beware of language such as "do what is necessary to save someone's life". It is very misleading. (Several medical people I have talked to had read the useful article 'How Doctors Die'.) Unless they're given other instructions, doctors have a legal obligation to keep someone alive, no matter how damaging, painful and ultimately pointless the methods of keeping them alive are.

B saw on my medical record that I had sent an email to Dr M (re red worm-shaped thing I'd hacked up) and hadn't gotten a reply. She talked to Dr M's assistant, who suggested I go over to the GP and ask

him if he thinks it'd be better to see him now rather than Monday. Which ended up meaning I was at the health center for about five hours (including the pharmacy.) (Also I had forgotten my purse! That caused some complications, most of which thankfully Tong bailed me out of.)

I like my GP, Dr G, who I haven't seen in years. As I suspected, the red phlegm resembles worms because they are in the shape of the bronchial tubes they are ejected from. Since I have allergies and asthma in my family, he said my cough could be caused by either, or bronchitis. I am taking antibiotics for five days. If the cough goes away, it was bronchitis. If it doesn't, it would seem to be one of the other two, which I guess don't have a 'cure'. Dr G questioned my oncologists' saying my cough was unrelated to cancer. How can they know that, he asked? (I wonder if they meant my cough is not directly caused by constriction in my lungs due to the tumors? Which is different from saying it's unrelated.) But I was tired and spaced out by the time I talked to Dr G and couldn't really answer some of his questions, or keep up with things in general.

February 25: **Thirst, fatigue, writing**

I seem to have found someone who will do chi gung/tai chi with me almost every day in Dolores Park. It feels great. He's not particularly gentle, but he's available and willing, bless him! He gave me a pep talk today. I wanted to take a photo of him doing a handstand against the fence but couldn't tell if I had his permission so didn't. (He just laughed when I asked.)

Had a good chin wag (I love that expression, British) yesterday with Elvin at Que Tal cafe. At the end he encouraged me to be more assertive with my doctors, which I think is good advice. I will need to get a CT scan at some point. Dr M is uncommunicative. I am not in a hurry to get another one. It's a lot of radiation. Plus what will it show?

I say that I don't have any symptoms, but I do get very tired, especially in the last week. Possible reasons:

Lung nodules sucking the life out of me

Allergies or bronchitis or some kind of virus

Being vegetarian (started that again this year)

Ordaining someone and leading retreats and having visitors.

(At one point after her retreat, Hridayashri was just as tired as I was!)

Also, I am thirsty, it seems, all the time. There seems to be some blood in my lungs, although I am pretty sure I am coughing less since starting the antibiotics.

February 28: **Hope and fear in the OC**

This morning I arrived at my dad's in Costa Mesa. I'm making him a lime walnut tart for his 83rd birthday tomorrow. He is doing better than I thought he was. He is sometimes repetitive but in other ways he is pretty mentally sharp. Laura and I will head for L.A. tomorrow night and the train to New Orleans.

I had a wonderful day yesterday. It started with an hour of chi gung at the tennis court with Teng How, a short nap upon my fatigued return,

Misha's for acupuncture, and the MBSR course I'm co-teaching with Bill and Allison. My body is sore from the chi gung but it makes me feel great.

On the table at Misha's, I visualized my lungs being healthy, healing energy coming to me from the universe, and briefly White Tara (archetype of long life and wisdom among other things) appeared above my head. Then I bonded with the guy, Drew, who came to do moxa and take out the needles. Usually the person doing moxa asks that I let them know if it gets too hot, but it never does, I'm assuming because of numbness. This time it did get too hot... does it mean there is feeling coming back to my feet? Or was he simply less timid? They do seem less cold. If it has changed it is very slow so it's hard to say. But I felt very happy when I was there and had a great chat with Drew, who gave me the all-time best foot massage (at least that I've ever gotten there, possibly ever!)

While there I thought, Ah, I ought to do this all the time: Maybe find a photo of healthy lungs and visualize them all the time, imagine healthy energy, in the same way that we "scoop up the energy" doing chi gung, descending into my lungs. (Of course I haven't done it since then but thinking about it was damned inspiring.)

Co-teaching the MBSR course is interesting. I know that we are helping people a great deal, well, people who are up to the task anyway. What's interesting is how my confidence in myself waxes and wanes. I sort of alternate between wondering if I'm a fuck-up or a

fraud and feeling incredibly inspired by what we are doing (and how we are doing it.) The class however is incredibly late for me, and the second half especially I was very tired. I got home at around 10pm. Anyway, I'm here now.

I spend much of every day looking after myself in various ways. People, including doctors, no doubt including me, have very strong opinions about what I'm doing, or have done, that helped, or not. Whenever I cough or I'm tired or whatever, some small voice in me is saying, Is it cancer? Is it happening now? Or it says, What if I went into, or am in, remission? What will I do? And yet another part of me hovers somewhere else, immune to hope and fear.

*

Separated

18 March 2009

Separated from love,

I access only

Other people's words.

Mine are locked up

Perhaps in imagined agency

As if to open, and to say

The word "opening"

Were the same.

Deepest longing

Cannot be uttered, but

Only painted

As a window shutting

Out rain.

Like others divided

I stare mutely skyward,

The wish sticks to my tongue.

Water slides over my eyes.

I would like to say
But won't, that
It's unbearable,
This centrifuge,
This disease.

Yet I remain.
Seeking what is essentially
Gravel.
Painting it.
Raining.

Rising and falling
From this canopy
Of fictions,

Landing
Safe and unsound
On the ground.

March 4: Paulette, Dad, Laura and me.

Dad is modeling the jacket I gave him (and got all OCD about 'cuz I was worried it'd be too small)



March 2013: House on fire

March 1: **House on fire**

Here's the poem I wrote recently. Some of its influences include: our flat and its occasionally disabled smoke alarms, the carbon monoxide detector at the retreat center, John Giorno's poem "Suicide Sutra", and the Lotus Sutra.

House on Fire

I.

It takes a while
To see the simplicity of
A sooner not later
Goodbye life

Ah, but here are
Alternatives to simple
As when one lies down
In a closed room
And smells smoke

Do I open the door?
Finish the book?
Scream for help?

How to overpower
My bewilderment

Again and again, I wake up.
The walls are hot.
No crashing, no sirens
Just a kind of wrongness
Unnoticed by
Public servants

The greatest
Nightmare is this, here
Watching the one episode
That burns, that gnaws
White sheets... red eyes...

Now is too much to bear.

II.

Here are two choices.
All of us must do one of them
Either the world is pried
From our fists

Or we let go
If only: of a sense of control
If only: of choosing my fate

In every now that I can find
The thing to let go of

Is me
One of the other things
Is you

III.

My house
Caught fire
I stroll outside
With the sky

March 4: **On the Sunset Limited to Louisiana**

Taking the train was interesting, though I have missed some key parts of my usual routine, such as naps, meditation, and exercise! One needs a certain amount of physical space, or more creativity than I have, to do these things. This morning Laura slept in and I went to breakfast on my own. I sat across from a woman who does seminars

on communication between men and women. She was very cool. We talked about brain plasticity and she pointed out that imagining exercise has an effect too! It's interesting chatting with people in the dining car. Grandparents from Wisconsin, vegetarians from Salem, Oregon. Bought a cowboy type hat with a wide brim in El Paso.

Having a cold drink or sorbet makes me cough for about an hour. Strong scents, detergents – things other people wouldn't notice – make me sneeze or cough. Touchy. That's a word for how my body is now. Well. My upper body. My lower body is... tight. Scarred. Temperamental? Maybe it's all touchy. None of it is a big deal in the grand scheme of things. I suppose it is a big deal to me, or an adjustment anyway. It's been over a year but I do not feel used to having a body that protests so much in response to ordinary situations (food, smells, air conditioning or heat).

A point I may have made before: Lots of other people are already dealing with what I deal with now. I did not have access to this information before; apparently there are secret societies in which common health complaints are shared. People my age and younger, and of course older too, have achey lower backs, uncooperative bowels, overactive bladders, numb and cold feet, inflexible hips, problems with lady parts, and/or allergies and coughs and environmental sensitivities. The body, either late in life, or early, or some time between, requires maintenance, demands forethought, crumbles into a pile before the mind, forcing the mind to acknowledge it.

It was fun being at dad's for his 83rd birthday. He is a sweet old guy.

March 6: **"Belief in" and voodoo**

We're all in New Orleans now – Paulette, Julie, Laura and I – in a groovy restored old house in Midcity, right next to the Canal Street streetcar. Bourbon Street is revolting. Even just the smell of it, though I can't say what the smell is. It's an intense culture, if it can be called that, of in-your-face sex and booze. Eg. an old guy standing outside trying to get people into a bar had a t-shirt on that began, "My Tongue & Your Clit..." The bartender at the absinthe bar the other day said she chugs alcohol to get drunk because she doesn't like the taste of it. One is tempted to say The Big Sleazy instead of The Big Easy.

My favorite thing yesterday was the Voodoo Museum, run by a white guy/voodoo priest. He gives a little introductory lecture on the way in, debunking all information formerly and erroneously possessed. At first the museum just seemed like two little rooms full of carvings, offerings, framed explanations of Voodoo, Marie Laveau, gris-gris, etc., plus dirt and dust. But then I felt something in there and I lingered for some time. For a while I was alone (the gals were all done and sitting outside) but in some way I did not feel like I was alone. I felt good in there. I made a ritual offering into a gnarled dusty tree stump – a wish wrapped in some coins. There's a little store (mostly handmade stuff) on the way out. I picked up something like what you would think of as a voodoo doll, but wasn't. Made mostly out of moss, they are meant as charms for wish fulfilment. I felt drawn to one and picked it up – the

man said the one I chose was for impossible situations, for someone who is terminally ill.

We got into a conversation. He told me that 30 years ago he had been diagnosed with terminal brain cancer. Because cancer is so detectable now, I wonder if it's a thing that just comes and goes in human bodies in a way that doctors don't know about, which is why you hear so often things like, My cousin was told she had two minutes to live, etc., and it's been ten years. You also hear about early detection for breast cancer causing more people to get treatment, some of whom don't need it.

It seems like people tell me these stories about outliving the doctors' predictions because they want to inspire hope. It sometimes seems like they're saying, This happened to me, therefore it will happen to you. While it shows that it's possible to outlive a grim prognosis, this angle on things is not inspiring for me because it says absolutely nothing about the odds that I shall do so. What seems much more a sign for me, in particular, is my continuing good health. Though even that has only been three months so far (since the grim December CT scan).

He did talk in terms of "when it is your time" which I find kind of comforting. Not in a deterministic kind of way, i.e., that 4pm on some particular date will absolutely be my time, more that at some point one's body is going to need to die, and no amount of juju or chemistry is going to change that. And, if it doesn't need to happen, it won't.

I know that many people think in terms of “believing in” something, or not. For instance, you could conclude, because I connected with the icons or whatever they are at the voodoo museum, that I “believe in” voodoo saints or magic. Some people can’t think of spirituality in any other framework besides belief. This kind of language is very strange to me. What does it mean to “believe in” God or saints or voodoo or bodhisattvas? For most people I think it means that one considers them to be real, ‘independently existing’ in a similar way, say, to a chair. I’m sure this is usually what is meant when someone says, “I believe in God.”

From one point of view, the voodoo museum was a few dirty rooms containing a bunch of inanimate lumps of wood and metal. That was not my point of view, though it makes sense to see it that way and I understand that. What feels right and natural for me at this point is to relate to the world – plants, objects – as if they had a presence of some kind. Not being a “materialist” (in the sense of seeing physical matter as the only reality, that everything can be explained in terms of matter and physical phenomena) doesn’t mean I “believe in” ghosts or rebirth or Apollo. However I do have a strong sense of felt realities that do not exist under the purview of science. The rational mind is beautiful. We can understand so many things, we can have extremely complex and useful ideas, we can evaluate a situation and strategize, and this is a large part of what makes us uniquely human (though in many ways collectively speaking we are also idiots!)

Anyway. In addition to the rational mind, overdeveloped in many of us by our hyper-rational, materialist culture, there are also... forces. Desires, instincts, hatreds, the unconscious – these are forces that simply exist. They can be thought of as within us – or beyond us – but in any case they are mostly not part of the rational mind. (It is in this realm where we perhaps discover the causes of the idiocy mentioned a few sentences back.) There are also other states of mind and attitudes – equanimity, love, clarity – that move beyond words, surpassing the rational mind. The rational mind is not to be disparaged; it is an important level of experience. It can't understand everything. As Hamlet says, There are more things in heaven and earth, Horatio, than are dreamt of in your philosophy.

I want to relate to the world as alive. I suppose that's called animism, which will, again, be defined in terms of beliefs I don't have. There are energies that are not accessible to a self-centered, literal, contracted mind. I am interested in those energies and in cultivating a mind that is receptive to them. Sometimes they can influence. I don't care if what I am relating to is 'out there' or 'in here'; it doesn't matter. What I believe is that the jumble of thoughts and beliefs that zoom around in our heads are not of primary importance. We are in fact hypnotized by our own thoughts, many of which don't do us any good at all. In fact they often make things more difficult than they need to be. I believe that what's important is what we do, and the mental states that motivate what we do. Everything else is, perhaps, as the Hebrew Bible says, vanity, striving after wind.

March 8: **Notes**

More notes on “belief”. I forgot to mention that there are two Americas in terms of childhood influences. One America ascribes to the religion of the rational mind, no spirituality of any kind, reliance on science, or on the popular media’s version of science. For another America, belief in God, and I would say belief in general, is primary. In this mode of thinking, systems that aren’t reliant on belief in an omniscient judge, or belief in general, are unfathomable. My background was more of the former, I probably don’t need to say.

Lots of “Buddhist converts” get weirded out by ritual practices that remind them of Christianity, either because it’s not ‘rational’ or, on a more emotional level, because it has negative associations. This is why much of Buddhism in the west has removed ritual elements and appears as completely secular, to the degree that people (who think they are being original) must often ask, “Is Buddhism a religion or a philosophy?” On the other hand, devotional practices aren’t inherently useful; in Buddhism one’s state of mind is primary.

Note: 11 hours sleep last night, and finally I do not wake up tired!

Note: We are having fun. (Quote from tour yesterday: New Orleans puts the ‘fun’ in ‘funeral’!) Today is our last day in Louisiana. We rented a car and are driving to Jean Lafitte Park.

March 11: **Back by the bay**

Some people got the impression that I didn’t like New Orleans. I loved it. I liked the culture and the history. I loved the food (just that it is

unhealthy, fattening, and not vegetarian!) I loved the voodoo museum, the street car, wandering around, and our bicycle tour... It's good to be home, too. All those cancer patients with their bucket lists. How do they find the energy? Loads of summer plans floating around, which I won't go into until some of them settle down. A couple things I have said in the last few days have made me realize that I now think of myself as someone who's going to live for a few more years. A change I will regret? Can't do anything about having one idea or another about a life expectancy anyway. Except, maybe, get a CT scan.

March 14: **Hair**

My hair is slowly getting thicker and darker. I owe it all to chemotherapy! Might be wavier, too. I can't really tell 'cuz it's still so short. Last time I got a haircut was 14 months ago. It's delightful having hair again, and I think it's better short.

Teaching the Stress Reduction class with Bill and Allison last night was good. I was really enjoying Bill's teaching. The class is 7-9:30 pm and I felt so tired during most of it I could barely function. (I don't think it's about how much sleep I get, because I get plenty and take naps when I need to. I think somehow it's the time. I can't think very well.) I have been thinking about looking into offering a class in the fall, but wonder if I'll have the energy for it.

My mom, who has Alzheimer's and lives in southern California, drove into a storefront window. Thankfully no one was hurt. Thankfully again,

Laura's going to make sure she doesn't drive anymore. Whew. We're going down there for her 80th birthday in May.

March 15: **News in the last two days**

Bill's mom went into hospice, as did another friend's mom. Allison and I will be teaching the MBSR class Wednesday. Chris, my dad's wife of 30+ years, is getting a lung biopsy on Monday.

I was coughing like crazy this morning, finally hacked up some bloody phlegm. (Very little blood, like one drop.) It's hard to cough up blood, it feels thick, it takes a lot of coughing! It occurs to me that at the moment I have the symptoms I was meant to look out for: fatigue, coughing, and coughing blood. (Other ones were weight loss and shortness of breath.) On the other hand everyone I talk to says they're tired, too. Am I tired from cancer, teaching, dust allergies, traveling? I've been traveling continually since October. I don't know. It's all guesses. I'll go to a doctor if my cough stays this bad for a while.

March 16: **Day retreat – renouncing and relaxing:**

led by Suvarnaprabha

Renunciation, or letting go, has long been an important part of the Buddhist tradition. While the idea may not sound exciting – perhaps reminding us of all the things we don't want to renounce – the practice is intrinsic to spiritual practice. Really, we let go in some way every time we meditate, each time we see, even in some small way, into our relationship to our world. It is

part of how we know – and can relax in the knowing – that nothing and no one – are ours. Letting go, releasing our clenched fists, is what allows us to truly grow, give, understand, and love.

The day will be a mostly silent meditative and bodily exploration of letting go. We will do sitting meditation, some of which will be lightly guided, and other useful practices, such as a body awareness, chanting, and gentle movement.

Suvarnaprabha has been deeply interested in renunciation, relaxing, and letting go for a long time – especially since she was diagnosed with metastatic cancer over a year ago. She has taught courses and retreats at the SFBC for over ten years, as well as internationally and at SF County Jail. She also teaches meditation for stress reduction in the wider community. She is currently writing a memoir of the last year, exploring, among many other things, this practice day's themes.

March 17: **So many ways of being old**

I have felt unhealthy since I got back from New Orleans. Again, all the plans I was making, especially teaching an MBSR class on my own, I'm sure that now I don't have the energy for them. I cough a lot and it hurts my head. I am tired, whether or not I can sleep. Of course my diet went south and I haven't been exercising enough. The change in health could be simply because of this. When I Skyped with Cull in Singapore the other day, she was hacking her little head off too –

allergies. Last night I took a Claritin before going to bed and I seem to feel better this morning, but who knows. There is a lot of construction around my house and there has been a lot of dust, which I am allergic to. (However, I cough while in other places too.) Then again my real coughing started on the day, or close to it, that they started construction next door...

My latest development in the decade+ of aging that has taken place in my body in the last year is my teeth. I've always had very healthy teeth. (A couple of years ago my dentist told me not to come back in six months for a cleaning, to wait a year.) Now I can see my gums receding and my teeth discoloring. The taste in my mouth is totally different, and I think why I am thirsty all the time is to get the taste out of my mouth, which never happens though it does get diluted. Short version: in the last three months, my teeth have gotten old. Healing with Whole Foods advises brushing with baking powder, which I did this morning. My mouth felt better.

My fingernails and toenails were also chipping and falling off in a new way for a while. At least I have groovy hair. Is that what aging is, more and more body maintenance until your entire day is full of it? For a while all you have to do is take a shower and eat occasionally, then it's medicine on the toes and yoga and teeth problems and hair on your face and allergies and asthma and medicines and teas and herbs and supplements and exercises for this and that... it takes all frickin' day.

I enjoyed leading the practice day yesterday. It wasn't perfect, but it was what I was able to offer. There is something about teaching which I really enjoy but I also find very challenging. It's not exactly the same as, but is perhaps derivative of, wanting to be liked. Yesterday I was not at all nervous which is unusual. I enjoyed being outwardly focused.

Someone gave me the book *The China Study*, which essentially I think says to be vegan. I realized that while I don't think there's any more nutritional info that would be useful or news to me, I certainly need to be reminded about the importance of diet. Keeping very strictly low glycemic index – vegetables – whole grains – low fat might be beyond my capacity for discipline. And yet, these things are likely a big part of the reason I am still alive and relatively healthy.

Helpful chat with Danamaya about allergies/asthma. Tomorrow I'm going to buy a mattress cover and wipe my windows off with bleach (they are moldy on the inside), and see what effect that has. Also started vacuuming and dusting today but haven't gotten to my room yet.

Sorry if this post wasn't quite as riveting as you had hoped. Tired.

March 18: **Some relief**

I spoke with the palliative social worker today for an hour and a half. We talked about the POLST form, about the Advanced Health Care Directive, and how hospice works at my health plan. I mentioned that I don't think my recent intense coughing is from cancer, but that one always wonders. One of the things she suggested is calling Dr M's

assistant and asking her if there is a way I can tell the difference between a cancer-caused cough and a cough caused by something else. That was a good idea (though there might not be an answer). That social worker is worth her weight in gold!

After talking to her and having falafels with Tong, I felt completely wrecked. (In truth I have felt wrecked for the last five days or so. I can barely function.) I drove to Bed, Bath and Beyond and bought a hypoallergenic mattress and pillow covers. I came home and lay on my bed unable to move much. Putting on the mattress cover was challenging! And I vacuumed my carpet and shelves and edges, geez so much crap in there, haven't even unpacked from New Orleans yet! I pulled stuff away from the windows and washed them with bleach, being super careful not to get bleach on my perpetually dark clothing.

I could have asked for help cleaning, but didn't really feel I could ask someone to clean out my crappy old carpet-layered and otherwise cramped and cluttered dusty moldy room. I do wonder if I will be able to keep living there. The construction next door is supposed to go on for a year. I'm also concerned that the mold on my window sills is "toxic black mold". The websites say that even after you kill it, it's still bad for you. They also say that those with allergies and compromised lungs are the most affected... I don't know what it is, but I feel terrible in that house for the last few days. Now I'm at Julie's. Her cats make my eyes itch a bit (that's also new) but other than that I'm golden. I have hardly coughed at all since I got here.

March 20: **Thoughts about food**

I'm reading Clean by Alejandro Junger, MD, which describes a 'cleanser' diet I am going to do possibly soon. Two friends have done it and recommend it. Some other friends did "The Master Cleanse" but I feel that, considering my condition, I want something gentler than that.

Many of us are very opinionated about food, thinking that what other people eat, or their ideas about health, are simply stupid. A friend recently scorned those of us who like "fake meat". Why not just eat tofu?, was rather testily asked. I've mentioned before noticing a friend commenting (without joy, let us say) on the food I'm eating as "Hm. Looks healthy." (And of course I don't think most of what that person eats is actually food!) I'm sure I am just as opinionated as 'the next guy', but I do try to reserve judgment about what other people eat. Really, it's none of my business. It's more the ideas about it that we get tangled up in. What one person says is healthy, another asserts is not... And the preferences are intense. As a culture we are confused about what we should be eating. Ideas about the good and the bad of eating habits sweep through America in waves.

Anyway. Whatever I know in my head does not necessarily translate into what I feel like eating, or what I am willing to prepare for myself. I'm hoping Junger's program will get me on track. I want to 'reset' so that I start craving things that are actually good for me again. This to me is the motivation to do a 'cleanser' or a special diet for a while.

I'm back home now. I still want to wash curtains, remove a layer of carpet, and dust more but so far the crazy coughing in my somewhat less dusty and moldy bedroom seems to be OK. I can still feel something when I am in this apartment... maybe congestion but not to the point of coughing...

March 21: **Discoveries**

This morning I talked to the nurse who works with Dr M. From what I described of my symptoms and what helps them (clearing out dust, mold, and taking Benadryl) she agreed that it sounded like allergies are what have been plaguing me. While acknowledging that cancer and allergies can share some of the same symptoms (in my case, fatigue, chest congestion and coughing), she said the kind of symptoms associated with cancer are: perpetual difficulty catching breath, difficulty lying down because of coughing, and a lot of trouble with any kind of physical exertion. I do not have any of this. She said she'd send an email to Dr M and my GP. I know that to most people, allergies don't sound like anything, especially compared to cancer. It really has been rather debilitating, though it's better since I cleaned things up a bit and got a mattress cover.

Something happened when I was walking to the MBSR (Mindfulness Based Stress Reduction) class last night. It was a big yet subtle change with mostly wordless content that isn't really possible for me to describe, but I will try to articulate... During the walk I noticed that I was feeling the usual dread and resistance. And after every class I think, that was good, so glad I did that. Not just this time, but literally

for years, this same feeling, and the same change of feeling. Suddenly I thought... what is this? It happens before pretty much everything I teach, almost a feeling of doom. What is it? And something unraveled. A deep and murky and unconscious thing. Something about being good, or good enough. Though it is subtle, an energy below the surface, I felt the locked-in quality, how it is tight and dark and completely self-absorbed.

At the practice day last weekend, I almost completely dropped it. It's so simple (but I assure you the process of getting there isn't!), but I felt a little underprepared. In some way I felt quite baffled about what to do. How to help people let go? I have no fricking idea. It just happens, you can't make it happen. But there it was on the Center calendar, a description of sorts about a day of letting go. While leading it I knew there was nothing to worry about. I was simply offering what I can offer, since there is nothing more than that I can do. There were a few times during the day when the thought arose, this is not good enough, but I let it go. It felt like stepping out of a cage. Several people have told me they really enjoyed the day and got a lot out of it. I'm happy that some people feel they benefitted from it; in a way, my attitude toward it stays the same.

Over the years I have often had some degree of fear or nervousness around teaching, at least in some situations. Coupled with a habit of ignoring fear and plowing ahead, there has been little opportunity to examine it. So walking to the MBSR class, there was a paradigm shift. I resolved to think of the class in terms of giving a gift, of offering

something. There is nothing much I can do right now about whether the gift is accepted, or even the quality of the gift. The gift is something about practice, based in my own experience, that I am trying to communicate. The experience of teaching, or probably anything, is painful (some of you will know the term, dukkha) to the exact degree that it's about needing affirmation of any kind or on any level. Not that you don't care if people get something out of it; more that you care in a way that brings more freedom.

The murky I'm-not-good-enough attitude was fascinating to explore. It melted under scrutiny and left a much freer way of being. It occurred to me how much anti-ego, which in Buddhism is the same as ego, I have brought to teaching, at least some of the time, all these years. It seems that this has changed a bit, at least for the time being.

March 25: **Oncology avoidant no more**

Kathy and Paris came from Singapore for spring break. We are in the mountains. I have an appointment with the allergy clinic on Monday and one with Dr M on Wednesday. She wants to check out my cough and for me to get an x-ray. Yikes! It makes me feel a little panicky. At least I got to be oncology-avoidant for a few months. That was sweet!

March 26: **The biology of beliefs**

I get a fair amount of book, movie, and video suggestions. One that caught my eye recently was the documentary [The Biology of Beliefs](#) (on YouTube) with Bruce Lipton. After a detailed and well-illustrated delving into cell biology, he shows how genes get activated by their

environment. He then moves to, but does not show, how the content of that environment must be comprised of one's perceptions or beliefs. The specific factors he mentioned that create a bad environment for cells were lack of love, and stress. I transcribed this from near the end of the film:

Beliefs act as a filter between the real environment and your biology... If your beliefs are off, you're going to select genes that are inappropriate for the environment... Here's the beautiful part: we can remove the filters that interfere with our lives.

The explanations of cell biology were excellent, and I liked the emphasis on the power of the mind. His angle on it is very positive: you can change your perspective and thereby change your cell environment. But the implication that the cause of disease is attitude bothers me. I don't doubt that some diseases are caused, and cured, to some degree by the mind. I don't doubt that there are diseases caused to some degree, and cured, by nutrition, physical activity, and medicine, or lack of them. Other factors I can think of right now: environmental toxins, genes. I don't think the guy is trying to blame people for getting sick, but rather encouraging us to be more aware of the effect of the mind. However, the implication is there, and it yanks my chain. Surely one's beliefs cannot be the sole cause of disease.

March 31: **More things people say**

1:17 pm. Sudden downpour. It sounds really great. I'm drinking a smoothie made of berries, mango, kale, spinach and misc. powders. I haven't done the full-on cleanse yet because I haven't read the book.

I realize that I am waiting for one of two things:

1. To develop symptoms, which will escalate for a few months until they kill me; or,
2. To not have developed symptoms for the number of months that indicates I'm in remission (don't know that number).

Either could happen. #1 more likely? It's very limbo-like, and not in the sense of the fun dance game you play in Trinidad (but maybe partly like that?)

I got a sweet card in the mail from a friend in England. Among other things, it said, "I will really miss you." From my point of view, this is like hearing, "After you cease to exist, blah blah blah blah." (I was laughing when I wrote that!) It's fascinating, some of the things people say/write to me. In any case, I love getting letters.

The issue of whose fault it is being sick, or assuming anything has psychosomatic causes, is touchy for me. I am surrounded by very kind people who tend not to accuse me of having caused my own cancer, however sometimes I do notice that people assume they know why someone got sick (he got the attention that he wanted through his illness, or how could she really have developed symptoms so quickly after getting diagnosed?) Or ideas or models that attribute

the cause of disease to the mind. Judging someone else's illness in this way upsets me, it doesn't even have to be my illness.

On the other hand, what does one say to someone who's dying or sick? We look at our future selves as if out of a Dickens story, and maybe start babbling to the spectre. There is a Buddhist ceremony (called *kalyana mitrata* or spiritual friendship) about which I won't go into detail, but just say that it involves two Order members. In my case, it was suggested that there be three Order members, which I've never heard of before. Obviously a backup plan for when I'm dead! I decided not to take it personally though it was tempting to do so. In a way it's better for me too, then I don't worry as much about the effect of my death on other people.

Sadly, my stepmom Chris, who my dad has been married to for 33 years, was diagnosed with lung cancer. She is feeling very poorly now and having a hard time managing my dad, who needs a lot of help these days. Much about her condition and possible treatment is still unknown, but it is very upsetting. It has, however, helped me to know more how people have felt about me. For example, I would like to see her, but I'm sure that is not what she needs. What she needs is help, not people who are moved to visit because she is sick. (Perhaps some people who are sick love visiting, and it depends on how much of an energy drain it is for the particular person.) Laura's going to be down there tonight to help them out for a few days. I hope I can do that some time but it depends on my own energy, visitors and other commitments.

We did the MBSR daylong yesterday. It's great working with Bill and Allison, and the best part was seeing how changed people's faces were at the end, so much gentler and more relaxed. But I just barely, if at all, had the energy to do it (or around 1/3 of it, which is what I did.) Today, my head hurts when I cough and I am spending a lot of time in bed.

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Constellations of kindness

20 September 2008

I am very aware when I am not feeling kind or I am having uncharitable thoughts. It's a definite physical sensation of hardness or tightness in my heart. Take a minute and think about where you feel non-kindness. What is a sign that you are not feeling kind?

Awareness and kindness correspond to the two main ideals in Buddhism: Wisdom and Compassion. The Wisdom and Compassion of a Buddha are perfected and unified, meaning that they are an intrinsic part of each other. Wisdom is not wisdom without compassion, and compassion divorced from wisdom is not compassion, or at any rate it is not a Buddha's compassion. But thinking more in terms of awareness and kindness can bring things down to a level we can relate to. We may not be perfectly compassionate or wise, but we can always be a little more aware, a little kinder. This is how we plod along in our practice, with a little more understanding, a little more love. I think that this is the most important thing in the world to do, even when it doesn't seem important, perhaps especially then.

Because there's so much pain in the world. This has not changed since the time of the Buddha. People being confused and angry and insecure hasn't changed. Things are more organized now, the numbers are bigger. We are probably more alienated from nature and each other, and have more self-loathing than the Buddha ever dreamed people could have. This is why Naomi Shihab Nye's poem

tells us that 'Before you know kindness as the deepest thing inside, you must know sorrow as the other deepest thing.'

So in our quest for kindness and understanding, we need to get in touch with suffering, especially in the form of our own sense of separateness, intolerance, or craving. Get to know it. At least, not shrinking away from it. We retrain our impulses by bringing them into mindfulness. This is an important part of kindness. And we realize, eventually, as Ajahn Amaro says, that even a headache has its place in nature...

April 4: Needle face. As you can imagine, it is not easy (or sensible) to take these photos with needles in my wrists!



April 2013: Officially dying

April 1: **Allergies please**

Today I spent about four hours getting allergy and lung blah-de-blah tests (you have to wait at least 15 minutes between each one) and a chest x-ray. During the various waiting periods, I read a beautifully written article (kinda long), called [“The Making of a Peaceful Death”](#). (I think I share values with my siblings, which I am grateful for.) My lung capacity is normal (FEV1=98%), so I probably don't have asthma. Danamaya told me the nodules may be in the tissue between the airways and this still appears to be the case. The doctor said my lungs sound clear, as I hope Dr M will say two days from now. After inhaling albuterol, my lung capacity increased to 106%. (Don't ask me how this is possible!) Now, my lungs feel irritated, and I imagine it's the albuterol so I'm going to have to be seriously short of breath to use that stuff.

The allergy tests were extensive. I seem to have fewer allergies than I had 20 or so years ago when I received a much simpler test. And, even more shocking, I am not allergic to dust or mold. I almost don't believe it! The doctor made the distinction between an irritant and an allergen. She said, with an irritant, the quantity increases symptoms. People don't tend to be as sensitive specifically to the quantities of allergens. (Almost) any amount of an allergen will set you off. I don't know. Still, dust hangs out on books and house plants. I may get

them out of my room anyway, because it is definitely an irritant for me, as are many other things.

I am moderately allergic to the pollen of cedar trees, certain grasses, and ragweed. That's it. These kinds of pollens tend to be around from April to October, exactly not the months that I've been coughing (January to present). She said my cough is probably not caused by allergies. It isn't in any way a bad cough, but this would explain why it's about the same all the time (except when it gets worse!)

She gave me two different kinds of inhaler (one for shortness of breath, one steroid to use twice a day), nasal spray, and... something else. I may just start with the nasal rinse Misha gave me, and see what that does. If my cough isn't caused by allergies, what might I hope to gain from taking all these meds?

So: my lungs are officially touchy. I can't be around people wearing perfume or cologne, cold air, I can't tolerate incense or any other kind of smoke, so many things to which the lungs, as Nancy Reagan used to suggest, Just Say No these days. Yet, I had a Hagen Daaz chocolate ice cream bar today. It was good, and it did not make me cough.

April 3: **Was that good news or bad?**

Crap, I got all attached to my life again. Which isn't to say that they found a tumor the size of a watermelon or anything like that... Just that based on the somewhat fuzzy x-ray, the nodules seem to have

gotten a little bigger. But the part that kills me (yes) is that there seem to be new ones.

Because she'd heard I had talked to the social worker, and my GP, and the nurse, about a cough, I am much healthier than Dr M expected. She also expected the nodules to have grown more than they had. She said that, by looking so healthy, etc., I made her day! And yet the same info seriously unmade mine. Just goes to show, it all depends on what you were expecting. I was expecting for the nodules to have stayed the same, or to have grown slightly. I was right about that (maybe, the CT scan will show for sure), but it never occurred to me that there would be new ones. A few hours after we left her office, it hit me like a ton of bricks. Enter Death, again, stage right.

Did I really think I was going to be cured, or healed? Well. People tell me it happens all the time. I seem like a reasonable candidate. But dammit, why didn't I remember that almost all the time, that's not the way it ends? That's why odds are odds. Really it's like saying, Hey, You'll win the lottery, happens all the time!

At first she was concerned about my weight loss. Well, I eat healthy food and exercise, and I wasn't doing that as much before, so why not? She said sometimes patients lose their appetite, but sometimes they eat a normal amount and lose weight anyway, 'cuz their bodies can't seem to do anything with the food. Maybe cancer is why I've lost weight. Why I'm tired. Why I cough. Why my mouth is dry and my

teeth are changing. Or not. No one knows. I'm not sure why, but today seems much more than before like waiting to die.

She did talk to Dr C at UCSF, who suggested roughly the same drugs as Dr A. Especially one called Avastin which was just approved by the FDA for cervical cancer. It's a 'targeted agent', something about it cutting off the blood supply to tumors. In the studies, I think people with ovarian cancer who took Avastin lived three months longer than those without. Which we thought didn't sound all that great! She explained, that three months is the mean for the group. So some lived longer than that, some less. Tenuous grasp of statistics here. She guessed chemo had a 15-30% chance of working, meaning that the cancer decreases in size by a certain percentage AKA 'there is response'. Come to think of it, I don't know if this was an example or a guess for me in particular. Alas.

Do I want to do chemotherapy? If only I could find out exactly why my tumors are growing slowly and do more of that. Do I want to do chemotherapy but only up to the point where the botheration (love this word, possibly coined by Danamaya) ceases to be worth it, then stop? She said most, if not all, of her patients want to be on chemotherapy all the time, that my wanting to just relax, etc., and not get any treatment makes me "one of a kind". Really? More comfortable on chemotherapy? Who are these people? Anyway. I don't know what to do (other than go buy a mint IT'S-IT from the corner store.)

I'm glad I didn't think to ask how long she'd guess I have to live. I'm not going to ask that anymore. No one knows. Even Dr M says cancer is a roller coaster, for everyone.

April 4: **24 hours later**

I don't have to be a model cancer patient. Sometimes death is there like a kitten purring on my lap, and it is fine. At other times, it's very sad. That's the way it is, nothing stays the same. I have let go of my life many times. Many times I have picked it up again; then just a momentary thought that it will be taken away, and streams are running down my face. Being fine can be being fine, or it can be a fence, or a mask. Or a fencing mask! Seriously though, I need a paradigm shift. I am fine perhaps too often. Or not that, as much as the rather deep feeling that I want to be fine, or I want to appear to be fine, that is problematic, habitual. Falling apart has got to become OK too. The word cataclysm springs to mind.

Today for the first time at Misha's, she asked me how I am, and my eyes filled with tears. She was really sweet. She suggested Levine's womb meditation, perhaps recording myself, then playing it back. Also books by [Elisabeth Kubler-Ross](#) about the stages of grief for the dying. I felt very calm after the acupuncture.

Need to finish all the damn paperwork, that will be a great relief. Perhaps I do have some imagination about a world that doesn't include me. There is no point in worrying about chemotherapy. I've

done it twice. I very deeply do not want to do it again, to take a gentler path, but that decision is for later.

I had some very sweet conversations today. Danamaya came over and we talked about giving help and receiving help, and how hard the latter is sometimes, and how being self-sufficient... leaves something major out of experience. And about dying, what it might be like to die in this flat that I've lived in for 19 years.

I can't imagine dying. I don't know what it will be like. I don't know what it's like to be cared for in that way, or indeed how that might happen. I haven't needed, or acknowledged that I needed, much help, possibly since I was somewhere between 5 and 10 years old. I've never even stayed overnight in a hospital. My cough seems to be getting more frequent. For example, I used to never cough when I was lying down. Now I do. There could be other reasons for this but at this point I'm going to assume that cancer is at least part of it. Though I'm still getting some amount of exercise, I am tired, every day. Some time in the relatively near future, I will get very sick over a period of time, I will perhaps be quite helpless at some point, and I will die. Who knew?

Hoaxes and gumption

There's a hoax email about cancer attributed to Johns Hopkins going around. It's a mix of ideas from science and alternative medicine. Overall, it's mostly sensible advice. For example, it says not to eat meat/animal products, and to eat lots of vegetables. Don't eat things

with added sugar or aspartame. It also says that radiation and chemotherapy scars and damages healthy tissues and organs. Some of it is obviously not based on science, like how not eating meat “allows the body’s killer cells to destroy the cancer cells”. (If that’s all it took, that would be very cool.)

But the detailed ‘science-based’ debunking of it is also not completely factual, or anyway does not accurately describe my experience. It says that chemotherapy and radiation do not cause permanent damage, which is just a lie! The neuropathy (nerve damage in my feet, though it is not painful) caused by chemotherapy endures. Radiation gave me arthritis in my hips. Don’t get me wrong, radiation is the main reason I am alive right now, but still, it is false to say that the effects are temporary.

What the rebuttal says about the immune system fits with my experience. Alt. medicine types seem to focus on cancer and the immune system. My immune system is fab and as long as you don’t x-ray my lungs, I appear to be healthy as a horse, if indeed horses are healthy. The danger of any point of view, ‘scientific’ or not, is thinking that if you do one thing, it will cure you, whether it be juice fasting or aggressive chemotherapy. If I had longer to live and more motivation, I’d meld what I consider to be the correct parts of both articles, from the point of view of someone with advanced stage cancer, who fairly successfully relies on both conventional and complementary medicine.

The last few days I've had the house to myself and have mostly stayed in bed, although yesterday I had a long wander around the neighborhood. I was planning to go on solitary retreat today, but don't really have the energy, or perhaps it is the gumption – a word I'm sure I've never used before – to gather up and transport the terribly many things I need to bring with me, get gas, and drive for three hours. I may still go. But not now.

Found a short book, 'Questions and Answers about Death and Dying' by Elisabeth Kubler-Ross, in Noe Valley yesterday. It's interesting, but unfortunately it's almost all focused on caregivers. I seem to have skipped three out of five stages of grief (bargaining, depression, anger, denial, acceptance) for the dying. I mostly stick to acceptance, with occasional bouts of denial.

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April 6:

Vanishing Lung Syndrome

by Miroslav Holub

Once in a while somebody fights for breath.
He stops, getting in everyone's way.
The crowd flows around, muttering
about the flow of crowds,
but he just fights for breath.

Inside there may be growing
a sea monster within a sea monster,
a black, talking bird,
a raven Nevermore that
can't find a bust of Athena
to perch on and so just grows
like a bullous emphysema with cyst development,
fibrous masses and lung hypertension.

Inside there may be growing
a huge muteness of fairy tales,
the wood-block baby that gobbles up everything,
father, mother, flock of sheep,
dead-end road among fields,

screeching wagon and horse,
I've eaten them all and now I'll eat you,
while scintigraphy shows
a disappearance of perfusion, and angiography
shows remnants of arterial branches
without the capillary phase.

Inside there may be growing
an abandoned room,
bare walls, pale squares where pictures hung,
a disconnected phone,
feathers settling on the floor
the encyclopaedists have moved out and
Dostoevsky never found the place,

lost in the landscape
where only surgeons
write poems.

April 8: **Thoughts on chemotherapy**

It's safe to say that the recent news of new lung nodules sent me into something of a tailspin on the theme of dying, which is very different from the apparently easier-to-take theme of death.

I talked to Jules yesterday about chemotherapy. She pointed out that some, if not most, of the 'miracle stories' about overcoming the odds with cancer were about people who had done chemotherapy.

Her relative who lived for 30 years with an 18 month prognosis was on and off chemotherapy the whole time, with periods of remission or stabilization. Somehow I did not know this, about her relative or others. What about the guy in New Orleans in the voodoo museum? He had also lived 30 or so years with a brain tumor. Had he done chemotherapy? I assumed not. BTW Elisabeth Kubler-Ross advises doctors not to tell their patients how long they are expected to live. Come to think of it, my doctors have never volunteered life expectancy numbers. They gave them reluctantly and only when pressed (by me).

My fears or reluctance about chemotherapy are many. One has been that it will decrease my life quality, possibly permanently (for example, if the neuropathy gets worse), and do nothing to prolong my life. And Dr M herself has said many times that she had no idea what would work, and that she would understand if I didn't want to do it. Ending up in the cliché cancer bed, dying, wrecked by chemotherapy. I'm very aware these days of various kinds of medical interventions that don't help, that do not consider quality of life, that cause suffering.

Part of it, too, is just the feeling I get when I think about periodically injecting super toxic chemicals directly into my bloodstream.

While it's also true that the other things I'm doing are probably slowing the rate of growth, chemotherapy seems the only hope for actually shrinking the nodules and prolonging my life. I remember what Dr A told me, that the disease was at a stage where any kind of treatment would need to include chemotherapy. Perhaps I will agree to do it for three months. Perhaps I will ask Dr M about choosing the drug that has the lowest instance of neuropathy. First let's see what the PET scan this week shows. She said there was no clear data as to whether starting it earlier gives better results. The only thing I know now is that I want to start before I need an oxygen tank.

April 10: **More from the dusty frontlines**

Hridayashri found the HEPA filter in the vacuum cleaner, which I cleaned and put back in. Then I took the vacuum apart a bit to clear it out, and tried to rid my bedroom of the layer of dust I created by vacuuming the super dusty 'picture rail' (I think it's called) yesterday. The HEPA filter is tiny. Does it really do anything?

Someone gave me an air purifier which has been blowing dust all over my room for the last few days. So I need a new filter for that, but the amazing thing is that Shantinayaka gave me just a regular dust mask, you know, for construction workers or whatever. I wore it the whole time I was in the clutches of vacuuming madness. Along with my Laney College goggles of yesteryear, it helped a great deal with the

coughing. I coughed maybe once or twice total, less than I have coughed in some time. Though breathing your own breath isn't the best part of that, but you get used to it. Some friends have suggested that I should ask (or pay) other people do these (ideally) dust-defying tasks, which makes sense when I am not using a mask. But with the mask, there is no reason for me not to do it. If my main job these days is staying alive, this is helping me do that, and I have the energy for it.

Robin left me some lentil-potato-kale soup yesterday. Yay! Lately, I am very motivated to do certain things, and amazingly unmotivated to do others, such as cooking or food shopping. Also my PayPal balance got to '0' and a few days later someone gave me \$250 which is very handy.

April 11: **Sugar**

Jules and I saw Dr E talk at the library for almost two hours. It was great. (Would have been improved if he had called me up beforehand to help him simplify his slides!) He talked about how sugar used to be special! Now Americans eat 20 times the amount of sugar we did 100 years ago. (Factoid: there are no sweet foods in nature that are poisonous.) Because I have been eating very little added sugar for over a year now (especially in the beginning this took some effort), seeing him was an affirmation. During Q&A at Dr E's talk, I asked about sugar and tumor growth. He mentioned a UCL study, which I looked up; it says:

Traditionally, glucose and fructose have been considered as interchangeable... and little attention has been given to sugars other than glucose. However, fructose intake has increased dramatically in recent decades and cellular uptake of glucose and fructose uses distinct transporters... these findings show that cancer cells can readily metabolize fructose to increase proliferation. They have major significance for cancer patients, given dietary refined fructose consumption.

As in anti-smoking campaigns, a federal effort should be launched to reduce refined fructose intake, the study said. BTW, table sugar is half fructose and half glucose. Dr E points out that the problem is not just with fructose, it's all sugars. Large amounts of fructose seem to be particularly pathogenic (causing cell damage, insulin resistance, fatty liver, and more). He noted that just about anything is toxic when highly concentrated and taken in large doses. I'm getting a PET/CT scan today.

April 12: **OK, I'm officially dying now**

Not to be melodramatic, I think it's realistic.

Misha was wonderful this morning. She put a lot of needles in my upper chest, front and back. My lungs opened up, and I stopped coughing. It felt so great. But as soon as I walk out I'm coughing again, though it probably won't be back in full force until tomorrow. I slept for an hour there, and I slept when I got home. I am much more tired lately.

I suspected there were more metastases, but since I am usually wrong at such guesses, I placed no wagers. But I was right. As with the new mets in my lungs, the reality went beyond my imagination.

Dr M called at around 4:30. We didn't even talk about my lungs. There is a 2 cm tumor in the left lobe of my liver, and disease in my spine, mid-upper back to the sacrum. There are also 'spots' – not totally certain that they are cancer – in my spleen and next to my adrenal glands.

I told Dr M I had warmed up a bit to the idea of chemotherapy. I did say of the various options available for chemo, I'd like us to pick the one least associated with neuropathy. She said Topotecan and Avastin are good, which was what she had in mind anyway after talking to Dr C at UCSF. She said if I am going to do treatment, it would be good to start in the next week or two. I told her I'd let her know next week.

Next week I will also ask her:

1. What would a decline look like for someone with my condition?

2. What can I hope to gain from chemotherapy at this point?

I had to tell Paramananda that I couldn't talk about the phone call until I was done packing and we were in the car. I'm at Jikoji now, it is very beautiful. But trying to figure out how to navigate among 30 people, many of whom will automatically say when they see me, after the American fashion, "Hi, how are you?" which is really quite terrible for

me. (I know that it's just what people say! But I'm pretty sure at our brief check-in, I'm going to ask them not to.)

April 14: **Coming home**

I cried on the freeway a bit, not much. My situation is much more painful in relation to other people than it is in relation to myself. I had the thought on retreat, *Dying Is Like a Thousand (Unwanted) Divorces*.

Padmatara made an announcement at the retreat. I wasn't there so don't know exactly what she said, but people were just friendly to me, and no one asked me about the PET scan, which is exactly what I needed. Friendliness and kindness are the best. Really, I was surrounded by cool and loving people. I am so grateful for that.

I hope to talk to R, the social worker in South SF, tomorrow about how to ask questions of my doctors. She told me a year or so ago that she gets the full story from doctors whereas their patients often don't. I thought I didn't believe her, or didn't think it applied to my doctors, but something stuck with me because I remember it vividly now and want her advice at this juncture.

In that story I read recently, 'The Making of a Peaceful Death', the dad is given chemotherapy because the doctor wants him to participate in a clinical trial, and the brother wants him to keep up the fighting spirit. It causes him a great deal of suffering, does not prolong his life, and he dies in the hospital completely wrecked and confused by drugs. My fear of natural death pales in comparison to my fear of this kind of

death. On the other hand, what if chemotherapy could prolong my life for a year? It seems so unlikely. I need more info.

I have a busy week with Paramananda here, Jeff coming tomorrow, and Paulette coming Friday. These people are among those I love the most, and yet, it feels like too much.

*

An Adventure

by Louise Gluck

1.

It came to me one night as I was falling asleep
that I had finished with those amorous adventures
to which I had long been a slave. Finished with love?
my heart murmured. To which I responded that many profound
discoveries
awaited us, hoping, at the same time, I would not be asked
to name them. For I could not name them. But the belief that they
existed—
surely this counted for something?

2.

The next night brought the same thought,
this time concerning poetry, and in the nights that followed
various other passions and sensations were, in the same way,
set aside forever, and each night my heart
protested its future, like a small child being deprived of a favorite toy.
But these farewells, I said, are the way of things.
And once more I alluded to the vast territory
opening to us with each valediction. And with that phrase I became
a glorious knight riding into the setting sun, and my heart

became the steed underneath me.

3.

I was, you will understand, entering the kingdom of death,
though why this landscape was so conventional
I could not say. Here, too, the days were very long
while the years were very short. The sun sank over the far mountain.
The stars shone, the moon waxed and waned. Soon
faces from the past appeared to me:
my mother and father, my infant sister; they had not, it seemed,
finished what they had to say, though now
I could hear them because my heart was still.

4.

At this point, I attained the precipice
but the trail did not, I saw, descend on the other side;
rather, having flattened out, it continued at this altitude
as far as the eye could see, though gradually
the mountain that supported it completely dissolved
so that I found myself riding steadily through the air –
All around, the dead were cheering me on,
the joy of finding them obliterated

by the task of responding to them –

5.

As we had all been flesh together,
now we were mist.

As we had been before objects with shadows,
now we were substance without form, like evaporated chemicals.

Neigh, neigh, said my heart,
or perhaps nay, nay – it was hard to know.

6.

Here the vision ended. I was in my bed, the morning sun
contentedly rising, the feather comforter
mounded in white drifts over my lower body.

You had been with me –
there was a dent in the second pillowcase.

We had escaped from death –
or was this the view from the precipice?

April 16: **Inside my thorax**

I looked up a lot of the words in the PET/CT scan report, which was probably a mistake. I wasn't even sure what a thorax was, other than a possible Dr Seuss character.

In more recent news, peeing has been painful for the last several days. Spent hours today, again, at the health center (mostly because it took me ages to have to pee even though I drank two large bottles of water), for an exam, urine test, and lunch with Tong. The results of the urinalysis were all normal except it contains hemoglobin. An internet search shows an association with cancer in the kidneys. Alas.

Paramananda, Padmatara and I are meeting Dr M tomorrow at 1:30. I wish I could share with you what R and I talked about yesterday – it might be useful if you have cancer or need to talk to doctors for other intense reasons – but there is too much. Jeff and I also checked out Fernwood cemetery, a beautiful “green cemetery” in Mill Valley. Can't go into that now either!

Just to say: I have a new self image that includes a lot more cancer. I'm not so bothered about what I eat anymore. I feel that the time for being careful has passed. (However, what YOU eat is important!) It is an intense time for me. In a way no different from normal life, but heightened somehow, and my mood changes seem to be all about life and death and my views about them. In the past I have sometimes seen myself, in groups anyway, as a walking reminder of death. Paramananda pointed out that to the people I know personally, there

is a depth and a tenderness there that goes beyond the abstraction. Truly, the tenderness is incredible.

In Buddhism we talk very freely about 'letting go'. And the reason to let go, or to have it as a goal, is that every aspect of our physical experience in this world, what we own and even our body, is borrowed. On some level we know this. Yet letting go of a loved one, including when the person is oneself, is tremendously difficult. Or maybe it's just thinking about it that's hard.

April 17: **Feeling betterish**

I feel sorry for all you Americans who did, or should have done, your taxes on April 15! I didn't do mine and it doesn't matter!

Paramananda, Padmatara, Julie and I talked to Dr M today. It was a good conversation. It made me feel positively cheerful. I told her about my fear of chemo. She seemed to totally 'get it'. She said she didn't know if I could fully appreciate how unusual my point of view is.

If I decided not to do treatment, she would refer me to hospice. Even though things seem to be spreading all over the place, the primary concern is still my lungs and my decline will probably revolve around them. There are so many ways things could unfold you can't really know all the scenarios. Bone pain can be dealt with in various ways including radiation. It's funny thinking about the psychology of it all. For me, the lungs aren't that important anymore, all the other mets seem disastrous. From a medical point of view, the lungs are, at the moment, 'still the main issue'.

So the drugs on the table, at first, were the chemotherapy drug, Topotecan, and the targeted drug, Avastin. The Avastin is pretty straightforward and can be combined with a variety of chemotherapy drugs. The Topotecan would mean I'd have to go to my health plan every day for five days in a row every three weeks, and all my hair would fall out. But when the hair loss came up and I mentioned I'd be sad to lose my curly new 'do', she said we could switch to one of the other drug options, Gemcitabine (jem-SITE-a-been). It doesn't cause hair loss, and it's administered only once a week for two out of three weeks. She said these drugs tend to be much more well tolerated than what I had before (CarboTaxol), and that we'd do a scan of some kind after six weeks (last time we talked, she said after two or three months). So it all seems very doable to me now. If it's not so bad, and it seems like it probably won't be, it could buy me a few more months of life.

R the social worker told me that people tend to live longer once they're in hospice. If I do the chemo, and I probably will, I won't be in hospice, because I'd still be getting scans and stuff, which isn't in line with the hospice principles. Once I stop, that is what will happen. I need to call the hospice one of these days and chat about things.

To clarify what I wrote about food last time (that it's not important), I'm not completely ditching the healthy food thing, although I seem to be not eating at home lately (which isn't that healthy!) I still want to eat food that makes me feel good, I just want to balance a bit more eating what I feel like eating with what is 'good for me' to eat. I had a few

glasses of red wine the other day which I really enjoyed. Haven't done that in probably a year.

I wonder if once I get ill, I could maybe sublet a ground floor studio apartment in a leafier part of San Francisco, or nearby? This apartment has 31 steps, plus, I think that I would like to be somewhere else, but close by. I hope that can be worked out...

April 19: **Chemo lite?**

Misha let me know that the treatment I had in mind wasn't exactly "Chemo Lite" as I had supposed. Avastin, apparently, can have very serious consequences even after you stop taking it. Because it's (ideally) stopping the blood supply to tumors, it messes with your blood. Looking at the studies is frustrating because much of them I can't understand. One study says all 11 ovarian cancer patients on Bevacizumab (Avastin) had gastrointestinal complications, fistulas, perforations, etc. Four of these patients died of the perforations within one year. I must ask Dr M what her experience with this is.

Yesterday was "Dutch Day". Viradamma and I had a great time at the De Young with the Vermeer and the Rembrandts, then later Tong and I went to see the primatologist Frans de Waal, who studies compassion and other moral behaviors (reconciliation, fairness, empathy, cooperation) in primates. He was funny, and he had great footage. Elephants doing puzzles that can only be solved cooperatively. A capuchin monkey (who gets a cucumber slice at the same time that another monkey gets a grape) throwing the slice back and banging his

fist on the ground. A three year old chimp looking thoughtfully through glass at a three year old human (kind of reminded me of the Rembrandt portraits actually). He also had amazing info about, of all things, the relationship between sympathetic yawning and empathy in general. It was cool.

I'm in much less pain after taking antibiotics for the bladder infection. I got an email though from Dr M today saying that the tests did not indicate that I have a bladder infection. Who knows!

April 21: **"This message will self-destruct in five seconds."**

I've been thinking quite a lot about moving to a quiet place with some trees around. It would be expensive. But actually the bigger factor now is all the work it would take to find a place. I'd like to be in a place that's quieter but not too far away, but it might be too late in terms of my energy level to look for it.

Brilliant meditation practice day with Paramananda yesterday. If I choose the right cocktail of lying down, sitting in a chair, and sitting on the floor, I can occasionally be super comfortable sitting on the floor, even when there is some pain. My sacrum is sore and my pelvic bones are not happy.

Anyway, it occurred to me that my body is self-destructing. In the old Mission Impossible, a tape recorder would convey the mission, and then announce its self-destruction and start getting all smokey. It's like that with my body, except the self destruct took around 50 years.

What was my mission?

My mom called me yesterday, which for other people is probably not that unusual. But my mom calls me around once a year, which has bummed me out a bit over the last while. Apparently Kathy told her to! Then she thanked me a few times for calling her. It was nice to talk to her. She said more than once how people in her family are long-lived and that she's going to live a long time. There wasn't much I could say to that. When she asked me how I was, I said that my body is full of cancer. She said it was awful to hear that. I said it was awful to tell her, then she moved on to another topic. It kinda helped me realize how she can't deal with the reality of my situation. Her 80th birthday is next month. I'm going to try to get down to see her, probably for the last time. I can't imagine how weird and intense that's going to be.

"The sounds of an MRI" would be an interesting post. Suffice it to say that it's a combination of the sounds of a laundry room, a machine gun, and a buzzer. At the end it was a BA-BA-BA-BA-BA-BA t-t-t-t-t-t BA-BA-BA-BA-BA-BA t-t-t-t-t-t in call and response. It was interesting to listen to (with my head in a vice, though a soft one).

It's funny how used to it I am now, people doing things to my body, shooting me up with "contrast", asking me about allergies, wheeling me into tubes, prodding private or public parts. As I have said before, keeping still in tubes while being scanned can be quite relaxing. I kept thinking today: How the hell is this thing looking in my brain?

I notice magazine articles often begin with sentences like, "Sam Smith was struggling with stage 3 prostate cancer..." " This is a case study

and may be interesting. But if one person is cured of cancer, by itself this really doesn't mean anything for anyone else. These kinds of things fill people with hope. A revolutionary new treatment was tried on Jane Johnson and now she is cancer-free! As I have said many times, it's terribly difficult for the dead people to tell you how the experimental treatment worked for them. And I haven't seen any articles that try to show their point of view. It would be too depressing I guess.

I know this is a lot of random points, but I just want to say that I do have cancer symptoms, perhaps little ones. Tonight my chest felt very congested and my voice seemed weird. It feels weaker, like there is no space in my chest. My sacrum aches for the last several days. I have less energy even than I did when I was on chemo before. Finally bought face masks today. I will make use of them. I (almost) don't cough at all when I have one on. Hoping my bladder infection symptoms don't come back. I wrote to Dr M and said I have concerns about Avastin and asked her about her personal experience with it. My sister Paulette and Paramananda are still here. We had a nice time today by Julie's pool.

April 22: **Extra, by Rick Fields**

Note that you may not 'get' this poem unless you are familiar with the writing of Shunryu Suzuki.

God is extra

I is extra

Extra is extra

Also like these lines:

Funny

how

in the light of death

everything

shines!

April 23: **Brain mets**

Ensure for food

Morphine for pain

Marinol for appetite

Kytril for nausea

Advil for sleep

Sit on the toilet

Shit and vomit at once

O This is ridiculous

And still

I'll sing my song.

from Fuck You Cancer, Rick Fields

I was going to write about how cool it was talking to the social worker yesterday, and some details about the areas she helped me with, which were huge for me, like a burden had been lifted. For that and other reasons, I got out of bed this morning feeling profoundly happy. Which is a good thing, because when Po and I were at Rainbow Grocery this afternoon, Dr M called and told me that the MRI showed brain metastases (several).

Though she left everything up to me about the chemo, getting radiation in my brain came with a strong recommendation. I told her I'd do it. Of course, I have no symptoms as yet, which is always very strange, until you think about the alternative. She said she didn't want me to start developing those kinds of symptoms. Nor do I. Three main things to look out for, and as she was telling me, I thought, Damn, I'm only going to be able to remember two of them. And so it has come to pass: headache, losing balance... Paulette and I conjectured that the third one was probably memory loss!

She sent me a copy of the report but I can't quite face it now. The big bummer news from my point of view is that I will in fact lose my groovy hair with the radiation. I don't feel that there's a real choice.

In a way, this news changes things. You think, Can this really be happening? Really? To me? But in another way, my overall situation is largely the same: body astonishingly riddled with bits of cancer, and the biggest bits are still in the lungs.

April 24: **Great Scott!**

I looked at the MRI report, and decided not to post it. Suffice it to say, the stuff in my brain is not minor. The appointment with the radiation oncologist is Monday afternoon.

A friend told me that I seem more grounded since I was diagnosed, which is probably true. I feel for people who are dying who can't face their own death, even to talk about it. They are missing a lot.

Drinking lots of corn silk tea to keep away the bladder pain (similar effect to D-Mannose.) And taking citrus flavonoids. Both suggested by Misha. Prasadacitta helped me with some yoga poses yesterday. I think I need to do them every day, or else my lungs feel, it's hard to say, smaller I guess, less spacious, to the extent that it changes my voice slightly, a bit higher, shallower.

Just took Paulette to the airport. She got my car detailed so now it's a cough-free-zone.

Just got to the section in the wonderful lectures entitled "[The Secret Life of Words](#)". I haven't listened to it yet but it's about war metaphors used in reference to disease.

April 25: **One thing, another, or both**

Waking up at 5 this morning I thought of Roseanne Roseannadanna from the old Saturday Night Live shows. She would say, "If it ain't one thing, it's another." Too true. Lately, seems like it's both things.

Probably was both at some point for the comedienne, too, who died of ovarian cancer.

Did I mention that when I talked to Dr M she was emphatic about me picking up a prescription for steroids (dexamethazone) that day? She wanted me to become a professional baseball player! Wait. That wasn't it. It was something about brain mets being associated with swelling, and also that I'd need to be taking them 48 hrs before getting radiation. So I'm taking them, and I was kinda happy because they give you energy, but much of the time you're still tired, just that relaxing isn't as relaxing. I will probably be getting more exercise though so that is good. Remembered (but did not have documented because of losing calendar) that I am giving a talk at the Gay Buddhist Fellowship on Sunday! Which feels like kind of a big deal. I will come up with something!

April 27: **A kind of goodbye**

Took Paramananda to the airport yesterday, after spending the evening and half a day at Half Moon Bay and Pescadero. We talked about death some, my death, but not a lot. It was mostly just the easy kind of being and conversation that happens with a close friend, and the subtle sweetness and sorrow of knowing that it is probably the last time.

I was telling Julie the other day that sometimes I feel as if I have some kind of contract or agreement with people that I am going to be around at some later date. I will work with you on this or that retreat in

two years, or in several years I will be there to help you with something, or do some project... a hundred little things. I couldn't even say what they are until I'm with the person and I am reminded of what I was planning on being there for. Then I feel that I am bailing out on all these assumed RSVPs suddenly coming out of nowhere, and I feel bad, even though there's not a damn thing I can do about it. Not that hardly any of this is even conscious. I'm feeling a bit sad today and that is probably coming out here. I'd like to get a sublet somewhere leafy and not foggy on the peninsula for a month, but not sure I'm going to be able to manage to look for and/or find one. Sometimes it seems that it is too late.

This morning, this came in an email from a friend in London:

The space in the middle [between double rainbows] is called 'Alexander's dark band'. I was very struck by that when I first discovered it years ago, and have felt so often that I am in Alexander's dark band – the space between rainbows which is darker than all the surrounding sky. Thought then that you've probably been feeling a bit dark-bandish lately, especially hearing about the cancer in the brain. It's very hard to remember when you're in that dark band that there are rainbows all round you. So the last photo is to remind you that there are rainbows. Big glorious glowing rainbows.

April 28: **Minor updates**

Friends have found some great sublet options. One hold-up is I don't know if I will need to be relatively close to South San Francisco where the radiation will happen, possibly daily... for how many days? I hope to know much more tomorrow. Feeling more congestion in my lungs. There is stuff I can do about it, but not motivated the last few days.

If you ever get a chance to give a talk at the [Gay Buddhist Fellowship](#), do it. Such lovely men!

April 29: **Brief**

Super long day today, and I am bushwhacked. Will write more tomorrow but for now, the short version is that we met with Dr O, the radiation oncologist. I will be getting "entire brain radiation" – which isn't exactly entire brain radiation because it misses the parts that are important to miss – starting this Wednesday for the next ten weekdays. It's actually much less scary once you talk to the doctors who deal with this shit all day, like it's normal. Thinking again about moving out of this room and this building, which I'm realizing is a bigger deal than I thought, almost a small death in itself.

If you are reading this, I love you.

April 30: **Anatomy and non-anatomy**

When there are more than three brain mets, the risk that there are other mets too small to detect is very, very high. That's why they are going to zap the whole thing. (I have about 15, some of which are tiny, and one is 3cm wide.) The dosage – or is it voltage? – is lower, and

overall it sounds like it could be less problematic than the five weeks of pelvic radiation I had before.

Dr O asked me to do all sorts of things to test balance, etc., and I passed it all with flying colors: no symptoms of brain mets whatsoever, and no swelling showing up on the MRI. And yet I am taking steroids (reduces swelling) that knot up my chest like a vise grip, and that's with only taking half of what I'm supposed to for the last few days. After a week of radiation, if there is still no swelling, I can stop taking them. I won't go into too much detail on the possible side-effects. Primarily skin irritation, hair loss (in a "reverse Mohawk pattern" – awesome – mostly after the radiation is finished), and some loss of cognitive function.

He asked if I want to try a drug called Memantine for six months (remember the radiation is only for ten days!) It's a drug developed for dementia that reduces cognitive decline from whole-brain radiation. He suggested it for me because he expects that I might actually live long enough for it to matter whether I have reduced cognitive function. We were all a bit surprised to hear this. I suppose that I still seem very much alive, and doctors seem to think this means something! In any case one patient he tried to give the drug to couldn't handle it – it made her dizzy. I told him I was worried about my lungs going wrong while we're working on the brain stuff. He said I could conceivably start chemo a week after radiation is over. Kind of wonder if I'm going to have the stamina for that, but maybe that will depend on how my lungs feel.

I went over to Oakland today and got a shamanic healing from Alan. It involved a lot of sound, and it was really wonderful. It brought me back to my heart, which is easy to separate from now that it feels so amazingly tense. It brought me back from the realm of the purely practical and anatomical to a feeling of deep relaxation, tenderness and love.

*

Hibernation

29 October 2010

I wake up in

Blackness.

I have fallen

out with the world.

My body swaddled

In caves.

Yet the pace

Does not slacken.

Yet I'm starting to

freeze.

Light shocks

My face,

Heats the liquid

Of my eyes,

All this is overdone,

Overwrought.

Full of moves.

All I need is

A source of water,

High-roofed caverns,
Light reflected off
Marigolds.

No reaching.

No digging.

No linking.

No rumbling machines.

There is no need.

It's all here.

May 8: One of the technicians took a photo for me today, Day 7/10. This is what it looks like, which comes as a surprise to me, too, since I can't see anything from inside that net.



May 2013: On being seen as “dead soon”

May 1: **Radiation was weird**

Stumbled in there after sleeping 4-8am, and nice people started doing things to my head, most of which I couldn't see, but I could feel the ratcheting down onto a table, and machines making noises, whirring around, and people posing cheerful questions to me when I am essentially gagged. There is not much effect or side effect, it seems, 'til after it's over.

Upon removal of the ratcheted mask I looked like a Star Trek character; felt a bit like one, too. Then multiple snafus trying to get prescriptions filled at the “convenient” pharmacy down there, which was a bust. Did you know that snafu is a military term from World War II? It meant “Situation Normal – All Fucked Up.”

I'm going to look for a house to live in, two bedrooms, on the peninsula, but can't really look at anything until after this weekend. The East Bay is a lot cheaper and I could probably get something twice as big, but right now it feels far away. Marin seems good for what I'm looking for, too, but even further away, and no train. Need to see what's available. Here on our little peninsula we seem to have a mental barrier to crossing bridges, or some of us do.

May 3: **Yesterday, and rental criteria**

Very nice time last night, dinner at Dhivajri's with people you may not know, but it was relaxing with great food, and I surprised myself being able to carry on some level of conversation. Earlier, lying on Misha's table, I was reminded of that scene with the blood-filled elevator in *The Shining*. When the doors slide open, it comes pouring out in slow motion, pounding out a river down the wide corridor. A violent image, but for me it was more about the chemicals that seem to be pounding through my body and hugely impacting my mind. It's such a strange experience of myself, I can hardly begin to describe it. It does involve energy. Lots of manic and possibly somewhat optimistic energy, and a kind of bodily confusion.

Besides whatever is caused by the brain zapping, the chemicals are Ambien (zolpidem) for sleep, Memantine (namenda), an Alzheimer's drug used for retaining more brain power after radiation, and dexamethazone, a steroid against potential brain swelling. Dr O just called and said if I haven't gotten a headache or anything after this weekend, I can stop taking the steroids on Monday. (Tapering down until then.)

Someone asked me what "the peninsula" is. San Francisco is on a peninsula, yes? The part that's just underneath (south) of San Francisco is called "the [rest of the] peninsula," the pink part on the map. The airport is there. Parts of it are like the Russian steppe with strip malls, parts are rather urban, parts quite rural and hilly, like where

we go on retreat. Belts of fog criss-cross it. Very different topographies and climates on the peninsula.

May 5: **Quiet**

I'm up in Lake County with Hridayashri. It is wonderful up here. Yesterday was very hot and sunny, today is much cooler and overcast. This morning we walked down to the bog and listened to the tonal cries of redwing blackbirds.

I did get a headache yesterday and still had it today, which is disappointing. Maybe this is just how headaches are, I'm not sure, I've had very few. It's not just that there is an ache in my head. It's that my head feels sore and tired and it doesn't want to do anything; ordinary things seem a strain. And it's somehow barely being held up by my body.

But 3mg of dexamethazone later I feel fine. I'm sitting out on the deck, surrounded by pine, cedar and oak trees. It is very quiet, a few dogs barking in the distance. A crow flies by and I can hear, rather loudly it seems, the beat of the wings.

Stopped at [Harbin Hot Springs](#) on the way here on Friday. Lying down on a bench there in a little cove, I started touching both sides of my head, and I burst into tears. Which is very good for me. I need to come back to my body again and again, not as a maze of unpredictable symptoms and speculations and pains, but as it is, as it feels, as a hurt friend.

May 6: **Waxy and puffy**

Taking Misha's advice, I put her preemptive herbal burn cream all over my head. I washed my hair five times this morning; it did not come out. Looks like it's full of "product" and leaves an orange stain. Ah, and a brief look at ingredients reveals: beeswax.

It is unclear whether or not my scalp will actually end up being burned. My guess is that it will. I just have to decide between a burned head, weird waxy hair, or prematurely cutting it, which would help with the burn cream but potentially show more bald patches later. Tonight Hridayashri put it on my head which I think will mean a lot less ending up in my hair...

Got thru day five of radiation with Karunadevi, so half way there. The mask seems to be getting tighter. When I mentioned this to the technicians, they said it's probably the dexamethasone making my face puffy.

At Rainbow Grocery there wasn't a single can of tomato soup without added sugar. It's not that I am not eating sugar. I've gotten more lax with that – it just bugs me now, unless I'm eating a piece of cake. Looking up Campbell's tomato soup I see that one can contains the same amount of sugar as a Snicker's bar.

I asked the other day to become what is called an "anagarika" (anna-GAR-ika) in our Order, which means taking an extra precept. Literally it means "one without a home". It pretty much means adopting a more monastic or simpler type lifestyle, or in my case making formal what I

am already doing. Another way of putting it would be to say making a formal commitment to stillness, simplicity and contentment in all areas of one's life. (You know, as a work-in-progress!) There are various obstacles to doing the ceremony in this country, including that there are no anagarikas in our tradition in North America. (It doesn't have to be done by an anagarika, but that's what makes sense to me, and if it doesn't happen I don't mind.)

What with my radiation and acupuncture schedule, getting out to look at places to live is challenging, though it's still on my mind. A brief sweep of Craigslist in the city reveals that one-bedrooms are around \$2,500. Going to have to be further afield.

Overall, today, felt incredibly blessed.

May 8: **What it is, or looks like**

One of the technicians took a photo for me today, Day 7/10. This is what it looks like, which comes as a surprise to me, too, since I can't see anything from inside that net. After they bolt me in, they line up the laser crossbeam to the bits of tape on the mask. That's how they get my skull in exactly the same position each time. Then they leave the room and the arm of the machine buzzes on that side of my head for a minute, then whirs over to the left side and does the same. Today they 'took some film', whatever that means, confirming the setup I think, so it took a few minutes longer, but the whole deal usually takes about three minutes.

Today we did talk to Dr O, who is a lovely sweet man. Might be the last time I see him. Hope so! Or there could be some 'gamma knife' (very focused high intensity) radiation in my future, to my lungs or brain or somewhere else...

May 9: **Fatigue**

I said that I'm taking 3mg of dexamethasone (steroid to counter brain swelling headache caused by radiation). Make that 6. I am math challenged when it comes to reading medicine bottles. Anyway, I had a wonderful reiki session with Tania yesterday and no headache this morning so only took 1mg, and I feel more like myself again. Misha mentioned today that dex. is very strong. It pushes me out of my body.

My hair looks really awful, like it's dripping wet, but I've been enjoying friends putting the burn cream on my scalp in the evening. I hope, but am trying not to expect, that it will keep my hair from falling out, or help less of it to fall out. Fatigue currently crashing its way up to the symptom front lines...

May 11: **She's not there** (again from Rick Fields)

Funny

how

in the light of death

everything

shines!

I'm down at my dad's, which used to be "dad and Chris's" but is not anymore, and will not be again. Absence is the first noticeable thing. The dog is manic. My dad's hair has somehow gone wrong. For many years, Chris was more energetic than any of us, and took care of everything with a quiet kindness and intelligence. I'm speaking of her in the past tense just because she is so suddenly, somehow, not here, and her absence is so felt. She is being very well-cared for in San Diego by her two daughters. We will hopefully be able to see her today once we pick up Kathy at L.A.X.. Apparently she is sleeping now most of the time.

Had a great chat last night about a variety of stuff with my uncle Roger and aunt Bev who drove down from San Antonio. They have virtually no health problems, which I was very glad to hear. That's how it often is in my family. Of course lately, in our immediate family, I seem to have founded the first metaphorical leper colony in an otherwise healthy clan, and some others seem to be joining...

This is an obvious point, but it's funny how when there is death on the horizon, the felt sense of what's important shifts a lot, naturally. I guess I'm pretty familiar with 'conscious change' in the sense of doing certain things to bring about changes or become more aware (that's essentially what Buddhist practice is) and then of course things naturally shift... but this is... entirely circumstantial. You see how in a few months someone's life just shuts down, and the looming fissure it leaves in their world, a world that for some amount of time will limp along without them. For me it's something about superficial

discomforts, a certain automatic amplification of certain signals in the mind. Say, being a little uncomfortable around someone, or getting weirded out in some way by what they say... even disagreement or conflict, however subtle or chronic.

The **Dhammapada** says:

There are those who do not realize that one day we all must die.
But those who do realize this settle their quarrels.

It's essentially this: the content of life is a lot of choppy water (it's the day for finding the right metaphor!) and when you're in a boat and there's nothing else to look at, that choppy water is the deal, it fills one's experience, it is important. But when one is aware of... the vastness beneath and how anything can stop any time, one is not so distracted by patterns on the surface. They seem to have placed themselves into perspective. They start to feel superficial, inconsequential. How do healthy people deal with it, with their friends and family dying off over the years? Are they just sadder? Is there insight into life and death? Does it make them more loving, more appreciative, or more bitter?

May 14: **On being seen as “dead soon”**

I seem to have a different projection for myself in terms of how long I might live. Sure, I have cancer in a variety of shapes and sizes – from a few centimeters down to a few millimeters and no doubt more that's too small to detect – in my lungs, brain, liver, spine, sacrum, and hip bones, spleen, and adrenal glands. This is what the mechanical eyes

that see into my body project onto the television. It's all on paper, on screens.

My daily experience is completely different from this, quite the opposite actually. I am dealing with drugs and treatment side-effects. But in spite of that, or no doubt sometimes because of it, and perhaps because of the excellent conditions I find myself in, I am positively burning with life. I think I may have another year or two in me yet, because of my "high performance status" in the words of Dr O, or more subjectively because I have no cancer symptoms. The degree to which I do feel sick is due to treatment, not disease.

It's also true that more than a year or two out, I have no future thoughts of myself stored in the "largely unconscious projections about the future" section of my brain, which used to have a lot more content. But for now, I do not feel, physically, like I am dying. I manage side-effects, but do not feel sick. I know that I will. It is not clear to me now that that will be soon.

Side effects update

On the plane back from Orange County I wasn't able to do an "easy" sudoku. It seemed really difficult. Then I started a "moderate" one and got more numbers, but many ended up being wrong. There could be other reasons for this, like lack of sleep, but it makes me nervous.

I have very itchy ear canals and throat, maybe from allergies or radiation, or both, a sunburned forehead, heartburn from the alz. drug (.05% chance of that happening), and somewhat painful urination

(could be fibrosis from previous radiation). I sleep hours less per night than usual, and wake up every hour or two, even when I take Ambien, which I used to think was strong. And my hair is starting to fall out.

Today is the last day of radiation, after which I will start tapering off steroids and get very tired. I will meet with the nurse afterwards and hear her suggestions.

May 14: **Surface tension**

Turns out most of the symptoms I listed yesterday are caused by the radiation. After noticing the nurse I was supposed to talk to seemed to be leaving for lunch, I ended up seeing Dr O. Apologies for the pangs of jealousy some of you got reading that. Dr O is popular with the ladies. It is hard to understand how one could go through medical school and have the job that he has and still be so sweet and sympathetic.

My forehead is bright red. Unfortunately they didn't tell me that was part of the deal, so I haven't been putting the burn creme on it. (He apologized!) My inner ears itch like crazy. He looked in them, said they're just irritated. The urinary pain is probably scarring/fibrosis from the last radiation I got. I just have to decide if it's bad enough for me to want some intervention, or if I can live with it.

Half-dose of the dex. for five days. Time to start feeling crap!

May 16: **Side effects galore**

I have so many side effects going on that I don't know if I can be bothered to write about all of them. Most distressing is the itchy ear canal. Way in the back of my throat, too. Who knew there were so many parts in one's head to get chafed? My eyes don't hurt, so there's that. At night I am mostly not sleeping for more than an hour or so at a time, probably because of the bladder issue. Overall I feel rather zombie-like.

The roots of my hair are very sore, and hair is vacating rapidly. Elaine gave me a Mohawk. It looks totally fricking weird, though much improved over the bald circles. I can't believe I'm saying this, but the chemo hair loss I had was better! Overall, losing the hair is a big deal. Hair, short or long, for a lot of women anyway, is part of normal, healthy, alive.

My anagarika ceremony is scheduled for the Order Day June 15. Parami is coming out for a long weekend. I wish I could provide a link to something that explains what this means in our Order, but I can't find anything. However, a few years ago I put together some writings about it, and if all goes well it will be [available in book form](#) [free eBook, ed.] on [Amazon](#) [print copy, ed.] in the next few weeks.

P.S. A few people have assured me that “easy” sudokus on airlines are hard!

May 17: **Flights of angels sing thee to thy rest**

This morning – or it might have been yesterday morning – I had a dream, or really it was more like being semi-asleep and hearing my

sister Kathy's voice. She asked if I knew that Chris had passed. I figured it didn't mean anything since I would have heard about it... but turns out she did die this morning. Our dark joke was that she was winning the race. She certainly did go fast, two months since the diagnosis. I am relieved that her suffering is over. She was a wonderful person.

I felt less horrible today in the various ways, for example, the itch in my ear canals wasn't actually pulsating. And I'm not as tired. Visited some with Dhammagita WHO BROUGHT QUORN SAUSAGES FROM ENGLAND. She claimed they were "vegetarian protein" with a lot of other food items. Customs didn't even look at them, surprising.

She also buzzed my hair. Since the hairdo necessarily operates in conjunction with the state of my head, it looks dreadful; however we are working with what we have here, which is a very messed up, burnt, hair-growing-in-moldy-jagged-patterns-looking cranium.

It actually feels good to do something with the mess that is my skull. Will I go outside like this or will I cave and wear the wig? Will I wear the wig to the lunchtime meditation class I'm teaching downtown next Tuesday? I'm thinking about not applying the veneer of healthy-hair-look over it this time, but not sure I want to deal with the reactions either. In any case, 'til the burns heal my head isn't going to be seeing the light of day much.

May 20: **Redaction**

Now I never should have said that I am burning with life. 'Cuz it ain't true anymore, or not much of the time. Sometimes, especially in the morning, I barely move, and when I do it's very slow, and the horizontal position fills me with joy. I wonder if taking the tiny amount of steroids I'm supposed to stop taking today is what makes it eventually possible for me to get out of bed.

I had two bodywork sessions today: a reiki from Tania this morning at Julie's, and a shiat'su with Dhammagita this afternoon back in the city. Both of them in different ways sent me relaxing and sinking back into my body.

I was thinking today that "how I am" moves between two poles – one end being relaxed and fully or more fully occupying my body. The other more about trying to "manage" everything on all the different levels. Medications and herbal pills, symptoms (actually, side-effects of treatment, I have no symptoms that I know of), medical appointments, bodily tension, 'complementary medicine' appointments and classes, decisions, analyzing.

When my body is essentially being assaulted in bizarre ways by treatment, and all kinds of management strategies ensue, the body begins to some degree to turn into a thing, which means that feeling is replaced by management strategy. Basically, more of the life force or awareness, I'm not sure what to call it, moves to my head and withdraws from my body. Coming back to a feeling that I can just be in and directly experience my body is always a great relief.

My 'look' now is tougher and includes lots of dark head stubble, an unorthodox Mohawk, and tattoos, albeit temporary ones. The hair down my head that looked like something's tail is smaller since more hair has fallen out. I find that normal facial expressions look harder, more angry. Maybe the red forehead is a factor too.

I noticed yesterday that my skull emits heat. The burn on my forehead seems to be dimming a bit.

May 21: **Needles counted, help, class taught, and partly fine**

Now is the season to know that everything you do is sacred.

Hafiz

Saw Misha and counted the needles in my head: 22. Got some weird pictures. Asked Tong to pick up prescription (brain helper), which I ran out of over the weekend. He kindly did so and left it in my mailbox where I retrieved it later. Trish is picking me up some corn silk (for tea) from Rainbow. I lost what I had (twice actually) and Misha says I should have it every day. And Dhammagita did some breath work with me this morning which increased my lung capacity, awesome. She also brings me delightful things, like a rubber baby's head that has a faint but unmistakable Mohawk.

I taught a lunchtime stress reduction/ meditation class today. It went very well. It's at a groovy shared workspace type place on 2nd street. However, it is fucking crazy that I am teaching this class at this time – which now that I think of it is probably a low point in the last seven or

eight months, if not longer! Fact is, I'm a little bit stupid, is the shorthand. Yes. Things you wouldn't have noticed as taxing in any way, like making a decision of any kind, reaching across the bed for something just out of reach, navigating anywhere, a flight of stairs, planning anything, driving, talking... blogging I can do lying down. But after many hours of lying down, I can have fairly normal energy for an hour or two.

Have an idea for an art project. A Wheel of Fortune with a symbol for each side-effect (they seem to do something of a rotation) and remedy. Or maybe a clock with many hands. Inside of a body. Or brain.

Listening to Tibetan monks with their super low voices chant healing verses ([Sacred Healing Chants of Tibet](#)), I'm really enjoying it.

I feel like crap on one level, and it is challenging responding to new limitations (and not knowing if I will have them for a few weeks, or many months). There's also some part of me that is fine, not wrecked at all. Even though right now I am very sleepy and my body aches, I feel in touch with it. Time to sleep.

May 22: **Handy**

Here's what I wish I had RIGHT NOW! Even Dhammagita, who generally speaking has everything you ever need, now or in the future, in her purse, doesn't have them! (She did have a few good cough drops, which is how I found out they're all not like candy.)

- A few cute, light hats that are not weird to wear inside. Trilby is one kind. Canvas short brim? (Fishing hat, canvas bucket hat?) I now have two in beige. A couple more, fairly neutral, would be fab. I will need them for months until my hair grows back.
- An overbed tray table (for eating in bed.)
- I was craving dill pickles for two days but that seems to have passed. Tong brought me an excellent, very spicy jar last night. (I ate four of them!)

I did stop taking the steroids, and life is much better without them, though they probably help me have energy that's more similar to other people. Itchy ear canals have stopped, and forehead much less burnt. However, so far I seem to have around 1-3 hours available per day of non-lying-down-activities. For example, today I was NOT lying down or asleep from 5-8:30pm. It is a huge mental adjustment, realizing that I am able to do almost nothing but lie in bed.

Apparently many people have given to a fund to get Parami out here to do my anagarika ceremony. THANK YOU THANK YOU THANK YOU.

May 29: **A homeless guy called me "sir"**

Perhaps for many women, being female is rather more obvious. Maybe it's the delicate bones or facial structure. But for me it's all about my earrings, hair, or whether or not I'm wearing a dress. I am

fairly tall, with broad shoulders. I'm not sure why it annoys me so much when someone calls me "sir"!

Taught the second class downtown today. I enjoyed teaching the class and think it's good, but it takes an enormous amount of energy in my current state. I realized that saying "it's only an hour" is ridiculous, because a shorter class is actually more work than a longer one. Anyway, half way through! Makes me appreciate even more teaching that class with Bill, who was holding the reins. Padmatara is coming now and will be backup if I can't do it, so that makes me feel much better.

Yesterday with the class and then seeing Misha I had to go downtown twice, which was extremely difficult. When I get really tired there is much more pain and coughing, but the good thing is that I do feel rejuvenated after sleeping, for a while. I took some time writing to Shabda, our monthly Order "reporting-in" journal. Here is what I wrote:

Dear friends, After receiving ten days of radiation to my brain (yes, it is very sci-fi). I'm also taking Alzheimer's medication (in a very recent study it was shown to reduce cognitive decline from brain radiation.) So I'm probably at least a bit dumber than the last time you saw me, and the fatigue is intense. And lying in bed most of the day is a good time to catch up on reading Shabda! Thank you to those who have wished me well.

My experience of the Order now is largely one of love and friendship. Having ended eight years of working for the Center,

and, in a way without the distractions of the difficulties that come up working with people and getting tasks done, all that's left is this very strong sense of connection, and the feeling of love that arises for people, not just people here, everywhere. I'm finding it amazing, not so much that Bhante created this Order, but that he even had the idea in the first place.

Because in my experience the prospect of death brings out love. Much of the love is tinged with sadness, but even that makes me realize what a gift it is to be able to love so many people, and to be loved. I confess that I was not aware of this prior to knowing that I probably have a terminal illness. Of course some of the usual barriers to expression have been removed, too, so much more gets said than it might have BC (before cancer). I feel blessed to be part of this Order.

On a related note, I just spent a most delightful ten days or so with Dhammagita. Not only was it fun but she completely barraged me with gifts, which I sucked up like a hungry ghost (albeit with a very large throat). Sad to say goodbye yesterday.

Many people think of me as a dying person. This is mostly not how I think of myself. It's true that a year or two more of living is probably the most I can expect, that recent scans of my body (plus a routine brain scan) in the last month surprised everyone by showing cancer all over the place, even though I have no cancer symptoms. In terms of my daily experience, I am focused

on life. The direction that my energy takes has completely changed to sort of interacting with my body, which is to say, mitigating the physical side effects of cancer treatment, and mental or spiritual effects as well. It is an all-encompassing task. In general, my orientation has almost completely changed from the future to now. I am still, at least sometimes, very much full of life, which of course will be more apparent in person than it is in writing. I remain cancer-symptomless, but after many different treatments in the last year and a half, all assaults in their own way, the side-effects seem to be piling up. I include in the side-effects all the different kinds of aging my body has done, mostly not visible, in a way that is beyond my 49 years.

Working with Vidyadevi to turn my blog [Crap! I've got Cancer!](#) into a book. Also, I will self-publish soon, also with her help, a collection of writings (from Bhante and other Order members) on brahmacarya called *Celibacy and Buddhism: Bits and Bobs on Sex and the Divine Life*. I'm thinking it will be on the best seller list in no time... Or else hopefully be a useful source of info for those looking for it. If anyone out there wants to do a second edition sometime – there is much more that could be usefully added – please do.

My anagarika ceremony will be on our Order day on June 15. Parami is flying out here to do the ceremony. (Fundraising for that initiated by Savanna in New York, bless her cotton socks!) My illness has pushed me a bit more into that way of life

(simplicity, and a focus on my body in a way that is naturally not sexual) so it feels like something that's already been done in a way.

I've spent a lot of time writing the blog for the last year and half, so have written into Shabda maybe twice I think. I'm going to try to write in more.

As my paternal grandmother used to write,

Armfuls of love,

Suvarnaprabha

*

Freedom on the inside: teaching meditation in prison

from Challenging Times, published by Windhorse Publications 2006

After five minutes I ring the bell and the chanting fades. We cultivate an attitude of kindness towards ourselves, and then towards all beings, including our enemies. The nervousness creeps back in. Is the meditation too long? There was some shifting around but during the last stage, in which we focus on all beings, everyone settled down. I ring the bell three times... The reverberations last a long, long time.

Some people take to loving-kindness meditation like fish to water. I understand these people. They look beautiful after they meditate, like they just got back from a retreat. The skinny new guy's eyes when they open look like he is in love, sparkling. I am careful not to stare at him. The white guy next to me says, "I'm sorry I was laughing, I didn't mean any disrespect. I'm sorry. I don't know what was going on, I couldn't stop, I didn't mean any disrespect. I couldn't stop."

The guy on the other side of him says to him, "I'm sorry I got mad."

I tell him he can be kind to himself about having had that experience. It's fine with all of us. "Yeah, it's fine," they all say. Everyone looks so kind.

Someone said he found the meditation very difficult, which I took to mean that he couldn't engage with it. He said that during the difficult person stage, so many people flooded into his mind that he would get really angry about it, then he would get angry that he was angry, and

so on. In a later class he said that his interactions with people had changed after he'd done the practice only once. He had never actually seen people as people outside of what he wanted them to be, and he had started doing that. The change seemed tremendously painful — suddenly to have that kind of awareness, to realize how it's been before, and to see how much painful work one has to do.

I remember when I started, against my will it seemed, to become acquainted with the violence of my own mind. I was on my first week-long retreat, and in one of the meditation sessions, my whole experience, my whole being and sense of myself, sort of filled up with awareness of hatred, and I saw with an indescribable immediacy what was underneath so much of my experience. I saw how at some level I hated myself and other people. Of course I also loved people, but I didn't love them how I love them now. That retreat was excruciating, as were many subsequent retreats. The path to happiness can sometimes be sad.

"I really want to change," an African-American guy says, another one who looked blissed out after the meditation. "Thank you for coming here, thank you," he says. People are very beautiful: I have to stop myself from looking at them. Some people end up getting out of jail and losing it — stalking their ex-wives, taking drugs again, both. Some of the yoga and meditation teachers get upset when this happens. Yet, I figure, doing some productive time isn't going to be enough for some people, perhaps most people, to transform a lifetime of addiction and violence. But while we're in the class, there is

something else going on, about peace and acceptance, something that seems to be rare – anywhere in this world.

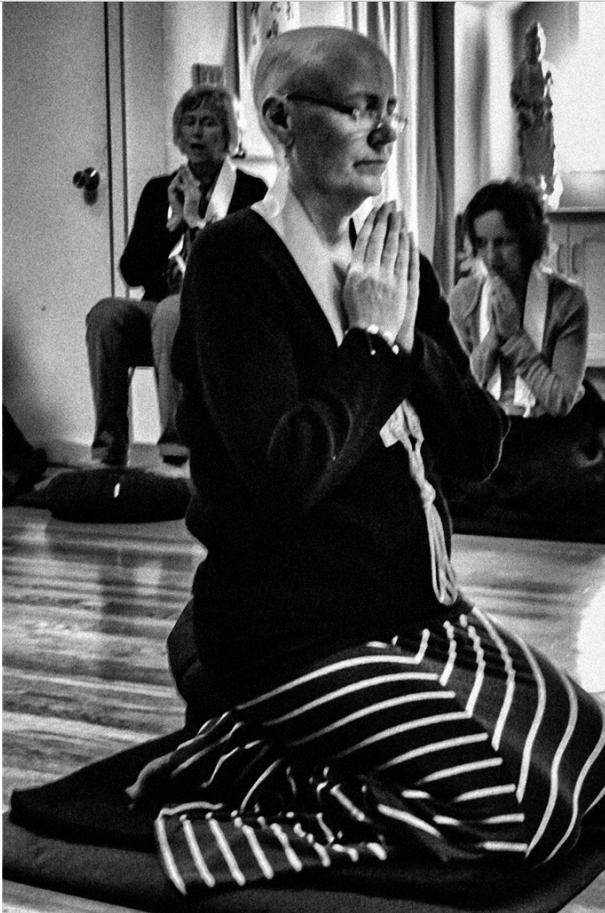
The guy with toothache says his pain's gone. Another guy says his headache has gone. Another guy throws his crutches across the room, stands up and walks. Just kidding – about that last thing.

Everyone looks so kind. There is love in the room. Transracial, transpenal, trans-sectarian love – the kind you can't actually define.

I press the button and a man looking at me on a screen in a booth presses a button. The door buzzes and we are outside again. When I get home I am so happy I can't sleep.

June 16: I had my anagarika ceremony led by Parami. It was very moving for me, although I was a bit worried the whole time about whether I would have the stamina for it.

Photo, Dhammarati



June 2013: What is being me?

June 3: **What I've been up to**

Not much! Enjoyed watching all available episodes of [Sherlock](#), a BBC series starring the impossibly named Benedict Cumberbatch. I don't feel depressed, which I'm glad about. I did not anticipate how doing ordinary things – anything that involves standing up – could take such an enormous amount of effort. Like standing up and putting on my jeans, or say, walking ten steps. It's a huge mental adjustment.

Ideally I would be drinking more corn silk tea and putting more moisturizer on my leathery forehead and skull, and doing some rudimentary form of movement. I'm doing a bit, just not every day. I'm very thirsty, and I am eating very little. Sometimes I only want to eat a specific thing (like dill pickles, pizza, or watermelon!) Especially when I get very tired, food sometimes becomes disgusting.

BTW my anagarika ceremony is 10am on June 15. Unfortunately it's "Order only" because of chanting the Ten (Order) Precepts. Hm, I just remembered I had a dream last night that involved some kind of threesome. I remember thinking, oh well, might as well do it before the ceremony! Yes, things have gotten a bit sexier as I figured they might. It's funny how in my dreams I am really into sex.

Jules came over yesterday and helped me out a lot while I mostly laid in bed. She brought food and cut up watermelon for me and took away stuff (mostly clothes that are too big or conservative) that I had in

a pile for a month or so. She also looked up “whole brain radiation fatigue” and reminded me that it usually only lasts a month, which is great news that I forgot. It’s been about two and a half weeks.

winter rain

people have been so kind

my eyes fill with tears

Santoka

June 5: **Skinhead**

You know how when you were younger and allowed your skin to get super burnt in the sun? And a few days later, in passing your hand across it, wherever it was, flakes of dead skin would wad up. My head is like that today, many layers of skin are coming off it. I took a bath and was astonished at how much skin was left in the tub. All part of the healing process I suppose. A couple of years ago could I have guessed that I’d be writing about dead skin in the bathtub on a cancer blog?

And occasionally coughing like crazy, tonight to the point of throwing up. There are simple things I can do that help this, like drinking hot water and using acupressure points. I did a bit this evening.

If I hadn’t started out being overweight, I would probably be too skinny now. Hopefully the appetite will kick in again before I get past a certain point. A friend made me some cornbread with weed (actually it’s only the butter that is cooked in weed). I tried one small bite and I must say

(after quite a while) I felt my body relax in a way that it doesn't otherwise. I think it helps with my appetite too. Today I had a slightly larger bite and later talking to Padmadharini I could not remember what I was talking about once I got to the second half of a sentence. That happened three times. Oh well, I had an excellent nap afterwards.

I got a sweet message from Dr K today asking how I am doing. I haven't seen him in quite a while.

June 9: **Golden throat lozenges**

Watching 'Girls' (HBO series) and a [documentary about Richard Attenborough](#).

I seem to be getting more tired, rather than less, which is disturbing. I'm sleeping more, and the amount of time I am able to stand up or even sit in a chair is shorter. I'm making an effort to eat more and hope that will help me regain some strength.

When I'm in bed, I started lying only on my back, which means way less coughing. Dhammagita says I might like these Golden Throat lozenges. If you can find me a pack so I can try them, please do! She got them somewhere in Chinatown. American cough drops, even the sugar-free ones, are too sweet for me.

All right, well, that's all I got right now!

June 12: **Prosaic update**

Laura's here and made an 8am appointment yesterday with Dr M, who said the reason for my fatigue could simply be cancer, or it could be a prolonged side-effect from radiation, or dehydration, or other things that I don't recollect. We talked with her for a while and then did various tests on various floors (they wheeled me around in a wheelchair). Chest x-ray, and an hour of hydration, and a trying time with a nurse trying to get blood out of a vein three different times. Finally she tried another vein and it was fine. The nurse called later and said I have a bladder infection which they want to give me seven days of antibiotics for. I've had it for two or three months, was getting used to it. I might have been able to get rid of it drinking corn silk tea. But I didn't. Botheration.

Life at this point seems to be a big chore, or more accurately an endless stream of chores, many of which I used to take pleasure in (or barely notice).

Dr M asked me if I was still interested in doing the chemotherapy that we talked about. I replied that I was still planning on it but I had also been planning on feeling a lot better than I do now. I wonder if I'm going to have to change the game plan on that. What if I don't regain my energy? Unknown.

Having said all that, I feel a bit more energetic now. I got the Chinese lozenges. They are very strong but not too sweet. If you have emailed me, or given me something, please forgive me if I haven't replied. I have not been able to keep up with things.

June 17: **Ceremony**

I had my anagarika ceremony yesterday, led by Parami. It was very moving for me, although I was a bit worried the whole time about whether I would have the stamina for it.

On other fronts, energy is variable, but mostly low. Some days I can hardly get out of bed and don't want to eat anything, other days the sleep is rejuvenating to some degree and I can do a few things. Overall, it doesn't seem to be improving.

Now what remains to be seen is whether or not I can manage to go on retreat for two weeks on June 22.

June 19: **Dr M in the morning**

I lost 4lbs since I saw her last (around one week ago) which I was surprised by, because I've been eating a little more. I caught a glimpse of the lung x-rays. They revealed that mets in my upper left lung lobe have caused it to collapse. Which is distressing but at least explains the shortness of breath and weariness. Apparently people can live with just one lung. At this point I have one and a half.

The brain MRI was checking for 'disease progression' only, since an accurate scan can only happen 2-3 months after radiation. Some of the smaller mets are gone and the largest one has shrunk, but there is some swelling around it. She suggested taking a low dose of steroids to help with appetite and energy (and swelling) and see how it goes. Cyberknife could be an option – it's a super focused kind of

radiation treatment for the brain and/or lungs. She's going to talk to Dr O about options.

I told her I would not do chemo unless I start feeling a lot better than I do now. She said she'd put me on hospice but since I'm going to be away she'd wait 'til I get back. If I do decide to do chemo she'd take me off hospice (apparently one can start and stop it like that).

My next appointment with her is July 8. I'll leave the retreat July 6, if not earlier. I imagine that it will be my last retreat.

It was a sobering visit, which probably hasn't totally sunk in.

June 21: **What is being tired? What is being me?**

For the last few weeks I would get the idea, for example, to open, or close, the curtains in my room, which are about ten feet away. Lying in my bed, I would think about it, off and on, for say an hour. Then I might decide not to, thinking it's really not worth the effort. Or I'd do it, and fall into bed afterwards, breathing heavily, to recover. I lay this out in some detail because I myself have a very hard time understanding 'the new tired'.

But, I don't feel that tired anymore. I can do a few things. I started taking 2mg of dexamethazone (steroid) yesterday but I had more energy before that. I'm still lying down most of the day, but I'm not sleeping as much. You know what else takes energy that I never noticed before? Humor. That's when you know you're really sick. It's impossible to make a joke. I really enjoy making people laugh. Not

being able to do much for myself and often not being able to make jokes, I can hardly recognize myself. People say I might be happier somewhere else, not cooped up in this room. But who's cooped up? Not me. I have everything I need here. Going outside is somewhat stressful. Going on retreat in a few days will be fine because once I get there I'll possibly do much the same thing (but in a prettier place, with help and meditation options).

How do I feel? A prisoner of my body, which is going to stop, and a certain level of acceptance of that. A lone polar bear swimming, scanning the horizon for land. Other people's sadness. Trying to get used to being a different person, or maybe just a different body. Eyes closed and a hand feeling around in a drawer for something lost. A clock. A future goodbye to myself. Taking off the hazmat suit. Looking at the ocean.

June 22: **On retreat**

I'll be at Jikoji for the next week or two. July 6 is the latest I'll be back, could be sooner. Love to you all.

*

Things as they are: fluidity and awareness

4 September 2008

They said, "You have a blue guitar,
You do not play things as they are."

The man replied, "Things as they are
Are changed upon the blue guitar."

And they said then, "But play, you must,
A tune beyond us, yet ourselves,

A tune upon the blue guitar
Of things exactly as they are."

I am in love with this poem by Wallace Stevens, which among other things begs the question, what exactly are 'things as they are'? The poem shows us that 'things as they are' are not solid, but mutable, fluid; not objectively frozen out in space but perceived by someone, by experience. And that experience, that fluidity, is a conversation, with both an active and a receptive flavor. That experience is both ordinary and extraordinary. It is a tune beyond us, yet ourselves.

All of which is beautiful, however, a bit abstract. In Buddhist circles and books, one hears a lot about 'being with things as they are'. What does it mean here? It means that you don't practice Buddhism or

meditate to become calmer, or because you told someone that you think you should meditate, or because you want to slow down thoughts, or lower your blood pressure, or even because you want to be kinder or change your life. We meditate because we want to be more aware, to know 'things as they are', in other words, to know what's going on in the deepest sense, inside and out.

Being more aware makes one kinder, calmer, and wiser. But the motivation is to be more aware, the practice, to practice being aware, and the action is being aware. And the more we hide or ignore certain realities of our experience, in meditation or in our ordinary life, the harder it is to cultivate awareness. The more deeply aware we become, the more natural, the easier, the purer our wish to be aware.

We all have mixed motivations. But I have found that when I want the results of meditation but do not feel interested in it as a process – a process of being aware – it becomes simply another way to suffer, however apparently subtle or noble. And of course outside of sitting meditation we can cultivate awareness every moment – we do not have to have special conditions for that, though some conditions certainly help. A cushion and a relatively quiet place to sit are useful. But mainly what's needed are a little guidance, spiritual friends, and most of all, the desire to be aware.

April 28: Here's a nice photo with Dayamudra during a Sunday wander around the neighborhood, which was wonderfully warm.



July 2013: Ghosts in my throat

July 6: **Sad elephants**

I can't summarize the last two weeks, but maybe I can say a few things.

The retreat was wonderful. Because I got a chance to really take in my current physical situation, not to say predicament. And because my friends took excellent care of me there, brought me three meals a day, gave me massages, walked with me up to the shower with a chair so I could sit down to catch my breath every 15 steps or so. I have never been the object of so much kindness before, as far as I can recollect. It takes some getting used to! It's so nice, too, to be in an environment again where the focus is on... well, existence really, one's own, and how one interacts with it.

Right now, breathing in sounds incredibly wheezy, like there are ghosts in my throat. Or sad elephants.

July 9: **Learning how to do things slowly**

Jules and my sister Kathy and niece Paris came with me to see Dr M yesterday, wheeling me around in a wheelchair, which helps a lot with the breathlessness I get from walking. Still, just getting dressed to go out continues to feel like a lot of work. I am learning how to do things more slowly, after a lifetime of zooming around.

Dr M was being very friendly. She actually made small talk for the first time ever. As we were leaving I was surprised to hear her say, "You're an amazing person." I'm not sure what she meant really but I'm glad she likes me. We talked about palliative options. She gave me a load of cough stuff to see if something can help. If it doesn't, some lung radiation (not Cyberknife) after a CT scan would be an option. Chemotherapy is off the menu. At the moment, I'm disinclined to do either.

My appetite is back, and I am sleeping much less. The coughing bothers me, and some hip pain. The most disturbing thing is not being able to walk or having to lie down so much of the time. Thinking back to my anagarika ceremony I see how exhaustion somehow reduced my personality to the bare minimum. I guess that was radiation fatigue.

Meeting the hospice lady today. (She had to reschedule to later because of the recent plane crash at SFO.) I miss my retreat massages. If anyone knows a good masseuse who makes house calls, let me know!

July 13: **Hospice first impressions**

Met with some of the hospice folks this week – an intake person and a social worker. They are super cool people. Here the focus changes to keeping one relatively happy and comfy, rather than merely alive. Also, they come to me, which is AWESOME, and they're available on the phone 24/7. I'll meet the nurse on Monday or Tuesday.

The hospice provides various visitors and some kinds of equipment, but no... I don't know what to call them. Caregivers, aids, workers. In other words, the hospice nurse and some other people are going to visit at specified intervals, once a week or whatever is decided, to help with medications/pain/any issues that arise, etc., but they're not going to stay for five hours and read me stories or administer morphine. (They can arrange this, which I would pay for.)

They delivered a hospital bed a few nights ago. It's small, looks and smells very hospitably and plasticky. I didn't sleep that well on it 'cuz of this layer that's on top of the mattress. It has these sort of pockets that fill with air... it's like lying on a carpet of hacky sacks. I deflated it a bit, we'll see. Being able to easily sit up in bed is great, which is why I wanted it.

Just got my feet rubbed by my niece Paris, and the catering around here has been excellent. Kathy has made spring rolls, spinach and ricotta ravioli, hummus plates, quesadillas... I'm feeling that I have a little bit more stamina, meaning that I can stay vertical a little longer. My mouth seems not so dry. Perhaps much of what's gone on in the last few months really was radiation fatigue, rather than a sign that I have eight toes in the grave.

July 24: **Somewhat stream of consciousness**

I'm finding it harder to describe my experience. Partly maybe because I'm talking much of the day. Not that that wears me out, but I am spending much less time alone than I used to, by necessity. There are

so few things I can manage on my own these days, and that seems to change a bit every day. For example, a few days ago I thought my stamina was improving, I was able to walk a bit further. I was able to take a shower standing up. The last two days though it's gone the other direction. After taking maybe ten steps I lie on my bed panting and wheezing for a few minutes, then I feel fine. Sometimes I cough a lot or hardly at all, or I have energy one day (relatively speaking) and the next day I have next to none.

Various people have suggested getting oxygen. It might not help but I will bring it up with the nurse next week. She mentioned last week that "young people" such as myself (I'm 49, I don't think of myself as particularly young, but I am a young cancer patient) tend to live beyond the six months estimated once someone is in hospice.

I've never moved my body so little. I've lost muscle tone. My skin is different. My body feels like a different body. Generally, my feet are cold, and my head and neck are warm. If I put the heating pad on my feet, it will feel good for a while, then my upper body starts to sweat. The nurse said many cancer patients have temperature regulation issues, so it's not hormonal as I thought. I have written for so long that I have no actual cancer symptoms, that all my symptoms were from treatment. Of course that has changed.

I woke up yesterday morning wheezing with my sacrum throbbing in pain. Before that I had been spared dealing with the shortness of breath at night. I tried some of the sublingual morphine. It wasn't

dopey like I expected, actually rather mild. Shortness of breath is the most deeply unpleasant thing I have had to deal with on this journey. It brings up an instant feeling of panic in my body. Moving slower and sitting down when I have to walk more than a few steps helps, but after a lifetime of zooming around it's a hard adjustment to make.

Saw Misha for acupuncture last week (felt great), my bed got sorted out, and I have a wheelchair now. Still have little desire to go outside. In fact, I don't have much desire in terms of doing things. Mainly I want to avoid the newfound challenges inherent in stepping outside this apartment. I thought I might be more adventurous. Not at all.

My three sisters were here from the four corners. That was good. They are all super sweet. I gave them all my old drawings (most are dated 1979 or 1982) which was a relief to me but seemed to make everyone else sad. Laura's going to stay for another while and at the end of this week, bring my mom up from southern California for a day or two. Also help me finish some paperwork.

*

The Matrix

from 'Ask Auntie Suvanna: solid gold advice for today's Buddhist'

My Dear Auntie,

My daughter is seven, and she watched the film **The Matrix** with me. She loves it, and wants to see the sequel with me too. So I was wondering: Am I a bad father? The other thing is, I recognize many Buddhist principles, such as the four noble truths, but I don't want to be a vegetarian, and meditating is no fun. Can I call myself a Buddhist?

Thanks in advance, Conrad

*

Dear Conrad,

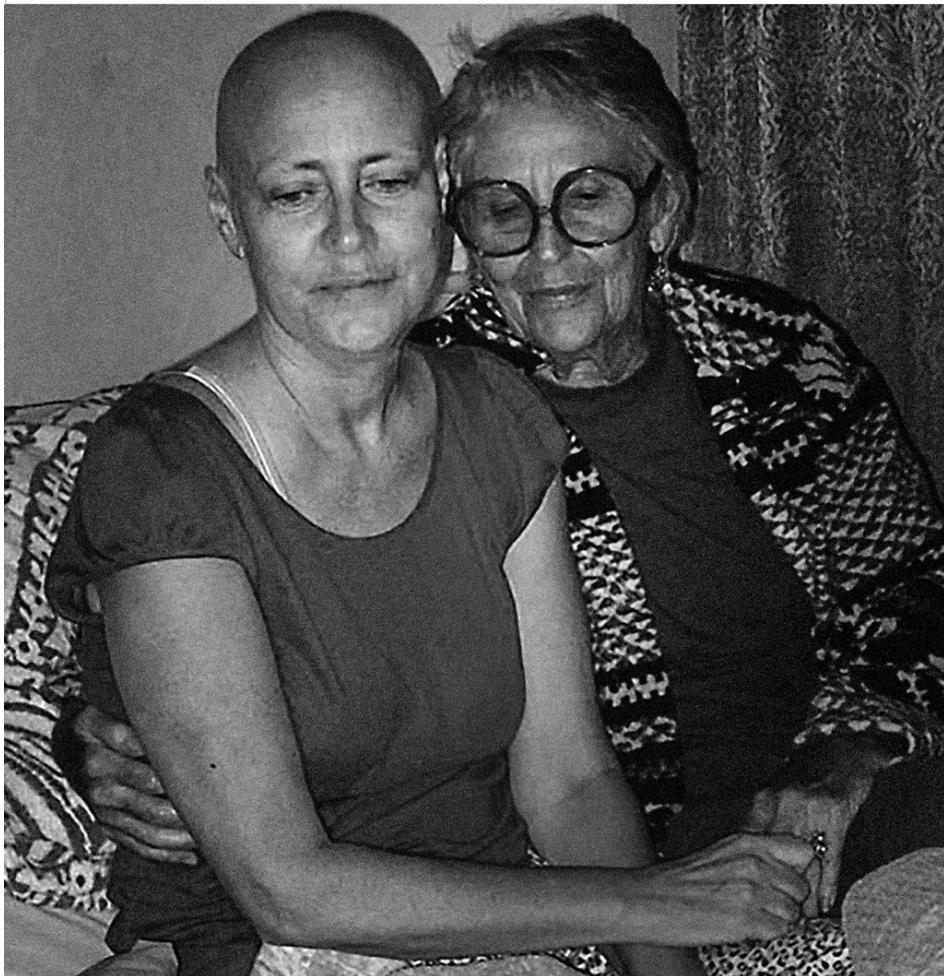
In reference to your first question, what else are you going to do with your daughter, take her to the opera? Be warned though that she will have a very hard time following the dialogue in Matrix Reloaded. Not that it matters.

And I'll let you in on a secret: meditation is great fun! Often we forget to tell people this. To prove it, I will recount an experience I had. Once after many days of meditating in silence, I walked into the bathroom and saw that the wall was covered with ants. (It was hot – spring in the Sierra.) The ants were moving in fascinating patterns. I was riveted – and stood there like a zombie, contemplating various implications,

staring at them for a long time. Now doesn't that sound like fun? Plus, it was free.

But let me venture a guess here a minute: instead of the above-documented fun of sitting for hours and hours and hours in silence, you prefer to spend those hours with your daughter watching violent special effects, right? Tell me Conrad, how long do you think it'll take you to get enlightened that way? On the other hand, if you stick to The Matrix (original) you can still be a Buddhist – just focus your attention on what Morpheus says and watch your breath.

August 3: Mom and me.



August 2013: The view from the inside

August 1: **Is cancer a gift or a battle?**

This short blog post on NPR (National Public Radio), “[Is Cancer a Gift?](#)” was interesting. It’s about a reaction to being told that cancer is a gift.

Is Cancer A Gift?

by Barbara J. King

There’s a gift in cancer. It says so right on page 203 of Greg Anderson’s book [Cancer: 50 Essential Things to Do](#) (2013 edition; first published 1993). Anderson quotes the singer Olivia Newton-John as saying this about her “journey through breast cancer”: “I see it [cancer] as a gift. I know it sounds strange. But I don’t think I would have grown in the areas I did without this experience.”

Then Anderson urges his readers to “Seek the gift in cancer. It’s there.”

Anderson’s way of putting things is no fluke; the cancer-as-gift trope is all too popular. Mark McKinnon used it in [writing for the Daily Beast](#), and Barbara Ehrenreich reports (but does not buy into) other examples [over at the Guardian](#).

In the two-and-a-half months since my diagnosis of a rare form of uterine cancer, I've not succeeded in locating any gift in cancer. I have discovered that, with the steadfast love and support of family and friends, I can deal with the effects of extensive surgery and of chemotherapy, ranging from discomfort related to the removal of various bodily structures including 29 lymph nodes and intense pain in muscles and bones that follows (for some people) an infusion of carboplatin and taxol drugs, to fatigue and oral thrush. It's hard work, this recovery.

But maybe the gift is yet in hiding and will appear sometime in the next six months as the chemotherapy regime and, later, radiation continues?

I don't think so. And let me clarify one thing: The hundred ways, large and small, that I'm shown logistical and emotional support from those who care about me is because of the generosity of the people in my life. In no way does cancer get the credit for that.

Ehrenreich is one of my guides on this topic. She concludes her essay on "the bad science of positive thinking" this way:

"Breast cancer, I can now report, did not make me prettier or stronger, more feminine or spiritual. What it gave me, if you want to call this a 'gift,' was a very personal, agonizing encounter with an ideological force in American culture that I had not been aware of before – one that encourages us to

deny reality, submit cheerfully to misfortune and blame only ourselves for our fate.”

Another of my guides is Lisa Bonchek Adams. Adams, also a writer, and a person with stage IV metastatic breast cancer, is a friend of mine – although we know each other through social media only, she is a friend nonetheless. On cancer-as-a-gift, she writes in a blog post [something that resonated with me](#):

“A gift is something you want to share.

“Something you want to give to someone else.

“Something [about which] you say ‘Next time I need to give a special gift to show someone I care, this is what I want to give.’

“Cancer is not that thing.

“Language matters.

“The words we use to describe illness, death, and emotion are important — we should choose them carefully.”

How right Adams is: *Language matters*.

Anderson, in *Cancer: 50 Essential Things to Do*, urges patients to “reframe” their disease and see it as “an inspiring challenge rather than a threat.” He also suggests some affirmations for the patient, ranging from *I am filled with hope* to *This is going to turn out perfectly* and *I am in charge of my cancer*.

It's no gift to suggest these last two affirmations to people with cancer.

There is no gift in cancer.

Communication is a sensitive thing, I suppose for everyone. How much more difficult when fear or grief, or just vague discomfort, are involved.

Perhaps earlier, more inspired phases of this blog would have driven the woman who wrote that article crazy. I don't feel that cancer is giving me a lot of gifts now, although from a certain point of view... whatever life doles out is a gift, or at least that's a more useful way to look at it, when possible, than the alternative. I guess this assumes there is some potential value in human experience, in whatever it delivers. I think of this as roughly equivalent to the views of those in other religions who strive to live with 'God's will'.

Which is the opposite of a fight, or a battle, the popular language these days in talking about disease. One model is rather more passive, or receptive. The other is, I am an agent of my own destiny, I shall think positively. Cancer and I are engaged in mortal combat, and I shall conquer it (and if I do not, I will have failed).

Telling someone how they should see things is a problem. The point I suppose is to learn how to be truly sensitive to other people, without our own views or advice getting in the way. It is not easy to do. It reminds me of a Buddhist teacher who said something like, The

greatest gift we can give is to be less of a problem to our friends by understanding ourselves.'

August 3: **Visitors galore**

The last few days I've felt better when I wake up, which is to say, not horrible. No more dizziness. And I am able to walk a few more steps than before. What changed? I've been trying to eat less (more appropriate amount for someone who moves very little with slow digestion caused by meds), and I started watching the British TV series [Shameless](#). Those are the only things I can think of! I did introduce a small amount of caffeine back into my diet which I'm enjoying.

When I seem to be experiencing an upswing in general, it could mean my stamina, etc., are improving for a while, but it also could just be part of the non-linear progression of my disease. My disease! I don't know if I've ever said that before! Anyway I enjoy being able to do a little bit more for myself (like walk into another room and walk back! Have a shower without needing to somehow build up the energy first.) Tomorrow's often a surprise.

Reading [Ursula Le Guin's The Earthsea Quartet](#). [NYT](#) in the mornings. Also: [St. Lucy's Home For Girls Raised By Wolves](#). [Inspector Singh Investigates](#). [American Gods](#). Can't really engage at the mo. with weighty topics. Also enjoying music – a French radio station, [fipradio.fr](#), and [Pandora](#) shuffle.

Visitors galore this week. Mom. Oscar from Seattle. Brothers-in-law. Many folks passing through on their way home from the retreat. Old pal Jeff is here now (from So. Cal.) currently making us an omelette...

The retreat I was supposed to be co-leading with Jayacitta [in Scotland](#) started yesterday. Thankfully the stellar Paramananda was able to replace me so that worked out very well. Well. For them! I'm sorry not to be there. I miss walking and cooking and zooming around, although in a way, not that much. Friends, having lives in the world outside this room, bring me their news, in person and on email, which I enjoy. You people have no idea how much energy you have.

August 7: **Caffeine, soup**

Had a cup of black tea and meditated with Hridayashri, my body buzzing with caffeine. Still, it was good to meditate, which I've done little of since cancer. I think I'm getting weaker. For example, the effort to stand up from sitting on what I wouldn't have previously noticed is a low chair. So, gadgets. Namely, a chair for the shower, and a toilet seat raiser. Both these things make life easier (though I sort of hate them, too).

I'm turning 50 in a few weeks. Don't know quite how I feel about that. Perhaps not overly celebratory. I had wanted to go on a cruise in Norway. Things have scaled back quite a lot since then. I guess I need to have a plan of some kind.

People often ask if there's anything they can do for me, and up until the present there has not been much. But I have lost a lot of

functionality lately. If you'd like to bring over some lunch sometime that would be great.

The compilation of writings I edited is available on Amazon. It's called *Celibacy and Buddhism: Bits and Bobs on Sex and the Divine Life*. I haven't actually seen it yet. I hope I remembered to get permission from everyone for reprinting! I need to get back to this book project before I run out of energy entirely.

On another note, here's the brilliant convocation speech [George Saunders gave at Syracuse](#). I read somewhere that he is a Buddhist which is not surprising.

Down through the ages, a traditional form has evolved for this type of speech, which is: Some old fart, his best years behind him, who, over the course of his life, has made a series of dreadful mistakes (that would be me), gives heartfelt advice to a group of shining, energetic young people, with all of their best years ahead of them (that would be you).

And I intend to respect that tradition.

Now, one useful thing you can do with an old person, in addition to borrowing money from them, or asking them to do one of their old-time "dances," so you can watch, while laughing, is ask: "Looking back, what do you regret?" And they'll tell you. Sometimes, as you know, they'll tell you even if you haven't

asked. Sometimes, even when you've specifically requested they not tell you, they'll tell you.

So: What do I regret? Being poor from time to time? Not really. Working terrible jobs, like "knuckle-puller in a slaughterhouse?" (And don't even ASK what that entails.) No. I don't regret that. Skinny-dipping in a river in Sumatra, a little buzzed, and looking up and seeing like 300 monkeys sitting on a pipeline, pooping down into the river, the river in which I was swimming, with my mouth open, naked? And getting deathly ill afterwards, and staying sick for the next seven months? Not so much. Do I regret the occasional humiliation? Like once, playing hockey in front of a big crowd, including this girl I really liked, I somehow managed, while falling and emitting this weird whooping noise, to score on my own goalie, while also sending my stick flying into the crowd, nearly hitting that girl? No. I don't even regret that.

But here's something I do regret:

In seventh grade, this new kid joined our class. In the interest of confidentiality, her Convocation Speech name will be "ELLEN." ELLEN was small, shy. She wore these blue cat's-eye glasses that, at the time, only old ladies wore. When nervous, which was pretty much always, she had a habit of taking a strand of hair into her mouth and chewing on it.

So she came to our school and our neighborhood, and was mostly ignored, occasionally teased (“Your hair taste good?” – that sort of thing). I could see this hurt her. I still remember the way she’d look after such an insult: eyes cast down, a little gut-kicked, as if, having just been reminded of her place in things, she was trying, as much as possible, to disappear. After a while she’d drift away, hair-strand still in her mouth. At home, I imagined, after school, her mother would say, you know: “How was your day, sweetie?” and she’d say, “Oh, fine.” And her mother would say, “Making any friends?” and she’d go, “Sure, lots.”

Sometimes I’d see her hanging around alone in her front yard, as if afraid to leave it. And then – they moved. That was it. No tragedy, no big final hazing. One day she was there, next day she wasn’t.

End of story.

Now, why do I regret that? Why, forty-two years later, am I still thinking about it? Relative to most of the other kids, I was actually pretty nice to her. I never said an unkind word to her. In fact, I sometimes even (mildly) defended her.

But still. It bothers me.

So here’s something I know to be true, although it’s a little corny, and I don’t quite know what to do with it:

What I regret most in my life are failures of kindness. Those moments when another human being was there, in front of me, suffering, and I responded ... sensibly. Reservedly. Mildly.

Or, to look at it from the other end of the telescope: Who, in your life, do you remember most fondly, with the most undeniable feelings of warmth?

Those who were kindest to you, I bet.

It's a little facile, maybe, and certainly hard to implement, but I'd say, as a goal in life, you could do worse than: Try to be kinder.

Now, the million-dollar question: What's our problem? Why aren't we kinder?

Here's what I think:

Each of us is born with a series of built-in confusions that are probably somehow Darwinian. These are: (1) we're central to the universe (that is, our personal story is the main and most interesting story, the only story, really); (2) we're separate from the universe (there's US and then, out there, all that other junk – dogs and swing-sets, and the State of Nebraska and low-hanging clouds and, you know, other people), and (3) we're permanent (death is real, OK, sure – for you, but not for me).

Now, we don't really believe these things – intellectually we know better – but we believe them viscerally, and live by them, and

they cause us to prioritize our own needs over the needs of others, even though what we really want, in our hearts, is to be less selfish, more aware of what's actually happening in the present moment, more open, and more loving.

So, the second million-dollar question: How might we DO this? How might we become more loving, more open, less selfish, more present, less delusional, etc., etc?

Well, yes, good question.

Unfortunately, I only have three minutes left.

So let me just say this. There are ways. You already know that because, in your life, there have been High Kindness periods and Low Kindness periods, and you know what inclined you toward the former and away from the latter. Education is good; immersing ourselves in a work of art: good; prayer is good; meditation's good; a frank talk with a dear friend; establishing ourselves in some kind of spiritual tradition – recognizing that there have been countless really smart people before us who have asked these same questions and left behind answers for us.

Because kindness, it turns out, is hard – it starts out all rainbows and puppy dogs, and expands to include ... well, everything.

One thing in our favor: some of this “becoming kinder” happens naturally, with age. It might be a simple matter of attrition: as we

get older, we come to see how useless it is to be selfish – how illogical, really. We come to love other people and are thereby counter-instructed in our own centrality. We get our butts kicked by real life, and people come to our defense, and help us, and we learn that we're not separate, and don't want to be. We see people near and dear to us dropping away, and are gradually convinced that maybe we too will drop away (someday, a long time from now). Most people, as they age, become less selfish and more loving. I think this is true. The great Syracuse poet, Hayden Carruth, said, in a poem written near the end of his life, that he was “mostly Love, now.”

And so, a prediction, and my heartfelt wish for you: as you get older, your self will diminish and you will grow in love. YOU will gradually be replaced by LOVE. If you have kids, that will be a huge moment in your process of self-diminishment. You really won't care what happens to YOU, as long as they benefit. That's one reason your parents are so proud and happy today. One of their fondest dreams has come true: you have accomplished something difficult and tangible that has enlarged you as a person and will make your life better, from here on in, forever. Congratulations, by the way.

When young, we're anxious – understandably – to find out if we've got what it takes. Can we succeed? Can we build a viable life for ourselves? But you – in particular you, of this generation – may have noticed a certain cyclical quality to ambition. You do

well in high-school, in hopes of getting into a good college, so you can do well in the good college, in the hopes of getting a good job, so you can do well in the good job so you can...

And this is actually OK. If we're going to become kinder, that process has to include taking ourselves seriously – as doers, as accomplishers, as dreamers. We have to do that, to be our best selves.

Still, accomplishment is unreliable. "Succeeding," whatever that might mean to you, is hard, and the need to do so constantly renews itself (success is like a mountain that keeps growing ahead of you as you hike it), and there's the very real danger that "succeeding" will take up your whole life, while the big questions go untended.

So, quick, end-of-speech advice: Since, according to me, your life is going to be a gradual process of becoming kinder and more loving: Hurry up. Speed it along. Start right now. There's a confusion in each of us, a sickness, really: selfishness. But there's also a cure. So be a good and proactive and even somewhat desperate patient on your own behalf – seek out the most efficacious anti-selfishness medicines, energetically, for the rest of your life.

Do all the other things, the ambitious things – travel, get rich, get famous, innovate, lead, fall in love, make and lose fortunes, swim naked in wild jungle rivers (after first having it tested for monkey

poop) – but as you do, to the extent that you can, err in the direction of kindness. Do those things that incline you toward the big questions, and avoid the things that would reduce you and make you trivial. That luminous part of you that exists beyond personality – your soul, if you will – is as bright and shining as any that has ever been. Bright as Shakespeare’s, bright as Gandhi’s, bright as Mother Teresa’s. Clear away everything that keeps you separate from this secret luminous place. Believe it exists, come to know it better, nurture it, share its fruits tirelessly. And someday, in 80 years, when you’re 100, and I’m 134, and we’re both so kind and loving we’re nearly unbearable, drop me a line, let me know how your life has been. I hope you will say: It has been so wonderful.

Congratulations, Class of 2013. I wish you great happiness, all the luck in the world, and a beautiful summer.

August 12: **The view from inside**

Today I was thinking about the book [Dying: A Natural Passage by Denys Cope](#), which a bunch of us were reading recently. It’s an excellent book – short, super informative and also comforting somehow. But it is from the point of view of the caregiver, as are all the hospice books, for obvious reasons. What’s it like for me? I thought I’d try to give a glimpse. Tonight I was lying on my bed for some length of time staring into space with the following list in my head:

1. Throw away the used dental floss in my hand.

2. Take a crap if poss.

3. Take some morphine to deal with this infernal cough.

The trash can for throwing away the floss is a few feet from my bed, by all accounts, not far. But it does require movement. Sometimes, moving even a few inches feels like an enormous effort. So I lie here – no idea how long it is – 'til due to some unknown force I laboriously turn over, pull back the curtain on my closet, and toss the dental floss (possibly to the floor if I miss!)

After a rest, a trek to the toilet. I sit there a while huffing and puffing to recover from the walk. Inadvertently knock over the little garbage bin. With my raised toilet seat I'm about a mile away from it. Do I just leave it? No, that's nasty. I manage to kneel down and put the spilled contents back in and set it upright. Rest a while. Crapping successful though always painful (multiple meds I am taking cause constipation, though other ones relieve it to some degree). In any case, my digestion happens very slowly.

I've been coughing like crazy for the last few days. Yesterday I coughed up some thick brown goo. The doctor that came a few weeks ago suggested that I might be less tired if I got a handle on the cough, which I am trying to do. Not so hesitant about taking the morphine anymore, which has been the only thing that will stop the coughing, besides making me feel super relaxed. Sometimes the cough syrup works fine.

So that's a snapshot.

Getting up in the morning involves many tasks that often take me a long time. Sometimes I fall asleep between things, and when I wake up my upper body, my neck somehow, is drenched in sweat. My body is full of surprises!

Some mornings I wake up and feel dreadful, low energy, and can't manage much at all. On others it's easier, things don't seem like such a chore. I feel better when I eat less.

Friends have been bringing over lunches, very nice food. Hot soup lately has been hitting the spot. I'd love to write about some visitors I've had lately, but I don't have the energy for that kind of detail anymore. Also, I'm working on my book (from this blog) and it is hard to work on both.

Now it's around 10pm, and I'm trying to finish this post before bed, but I probably won't. My laptop is on my table, and I am lying on my bed typing this with my left hand, listening to flamenco guitar on Pandora...

August 14: **By way of contrast**

Woke up feeling rather chipper this morning. Everything not such a slog. Possible factors: Hydration – been drinking lots more. Had been getting super dehydrated at night (partly due to drugs.) Recovering more from brain radiation in May? Ears and forehead have stopped peeling also. It's not about eating less, as I ate like a sow yesterday. Or was it Laura's awesome foot massage? Reasons perhaps are unknowable, but I am enjoying it.

August 18: **Pharmaceutically-enhanced living**

Today I was grateful for modern medicine. I can't do much when I am coughing a lot, it's very hard on my body. I can barely pull myself up from my bed. After trying cough syrup, I took 2mg sublingual morphine, and a few minutes later my cough stopped. The difference isn't even primarily coughing vs. not coughing. It's exhaustion/tension/restlessness/slight panic vs. relaxing. It feels like my lungs are getting very small, too small for breathing almost, then that tightness melts away.

Then my hips started aching. Took two ibuprofen and a little while later, I feel great. Come to think of it, I guess without the treatment I got, I'd be dead now. It's supposed to keep you alive longer, which it did, in my case anyway, with a high quality of life. Got the suggestion to try marijuana instead of morphine. It seems actually rather complicated figuring out the how and what of medicinal marijuana (i.e., the best use for me, if any).

Jules, Padmatara and Laura are here. Mary Jo and a doctor came this morning. All kinds of equipment I could get that would be helpful. Though I am weak, I'll probably wait 'til I can't do without them.

August 22: **I don't recognize my arm**

My body is turning into a different body. Mushy would be one way to describe it. I look at my arm – the skin and muscle tone – and it reminds me of the arm of my grandma Bruun, who died many years ago. And even the most mild physical activity somehow makes me

feel worse, makes my lungs ache and pant and wheeze for a while. What my body wants, craves really, is to lie still. But it seems from my current point of view that moving is what keeps you alive. It's the reason you can digest food and get tired and walk without falling.

So many things to let go of.

My birthday was fun, saw more people than I thought I would want to!

August 23: **What is a waste of time?**

Every day I look at **Facebook**, which usually means finding out what someone did today, what they're thinking about, clicking a more or less interesting link, or looking at photos. I don't post anything myself. I look at **Twitter** and the New York Times. I play **Bejeweled Blitz** (a one minute game). I don't spend all day doing these things, but do I want to be doing them at all? Sometimes there is a rare gem, like Saunders' speech the other day.

I'm not going to agonize about it. For the moment I'm just, as **Rilke** says, "living the question".

Had a good chat with my dad today.

Ordered some Dutch and Finnish licorice online. Laura is a fan, too.

On conflict with friends

25 May 2010

There are those who do not realize that one day we all must die.
But those who do realize this settle their quarrels.

(Dhammapada, transl. Buddharakkhita)

Many of us have virtually no experience of honest communication in response to disharmony. We have known too much criticism and blame. We have no training, no models. If we manage to say anything, we speak in sweeping generalities, or inadvertently assassinate someone's character, or seem to just want to be right. We are afraid to share clear and kind information about how things affect us. We fear losing love.

Sometimes irritations fade away on their own. And sometimes we rationalize failing to respond honestly to a repeating situation. Maybe we think we should be able to resolve it on our own (a near enemy to 'taking responsibility for one's mental states'), or we have the excuse that the other person can't handle honesty, or we are sure they won't change so there's no point, or out of fear we decide to avoid the person... or we just try to say something and can't. Any of these sound familiar?

And so it builds into a burden. Each time the thing happens, the situation becomes more entrenched. We're too annoyed or exasperated to bring it up. And when things are good, bringing it up appears to be totally unnecessary.

What can be done? We can learn the basics of Nonviolent Communication and practice it. If we don't want to do formal NVC, we can keep in mind the basic principles. One of the most useful ones for me has been using very specific examples. Consider potential responses to "When you closed the door last night, it woke me up." vs. "Why are you so inconsiderate and always slamming doors?"

My advice to myself is:

1. If there is some issue or resentment that keeps coming up, make a point of bringing it up with the person when things are harmonious.
2. Look deeply at your motivation for bringing it up.
3. Though it may end up helping the other person, do not think of that as the purpose. Think of it as a way for you to practice engaging more honestly and effectively with friends.
4. If you think it will be hard for you to articulate it skillfully, practice with someone else first until you are more comfortable.
5. State the reason for bringing it up. Example: "I have noticed I have some resentment toward you, which I feel is kind of a barrier between us. I was wondering if it would be ok with you for me to try to talk it through."
6. Don't speak in generalities; use concrete examples.

7. Remember it is not the other person's fault that you feel how you feel. However, they were an influence, and you are trying perhaps awkwardly at first to share with them how things are for you.

8. Is there a specific request? If so, be clear about what it is. Don't ask someone to overhaul their personality. They can't. Let them know how something specific affects you and ask if they are willing to do something specific related to it. They are free to say no.

9. Remember that even if the person has a bad reaction, the conversation still may have some benefit. If it doesn't, at least you tried!

10. If misunderstanding increases, re-state that the reason for bringing it up was to connect more deeply, and apologize for any unskillfulness on your part.

Summer retreat sunset



September 2013: The view from the inside

September 5: **How much life?**

Changes in the last week or two such that I'm not sure where to begin. On Monday it was suggested I take morphine and ibuprofen for pain and coughing regularly rather than "as needed". By medical standards it's still "not that much". So I did. Result has been no pain in my hip bones and knees, and less coughing. And dozing in and out of sleep all day. I'd resolve to finish my paperwork each day this week, but I simply haven't had the mental ability. Laura – bless her cotton socks – was helping.

Part of the cause of all the sleeping is that typing on my laptop in bed is so unergonomic that it was causing new pain in my side, the way I'd prop up on one side for hours typing with one hand. So then I didn't want to get out my laptop, which weighs hundreds of pounds (and is usually a hundred miles away!) Using the phone is pretty handy but you can't do everything on a phone. But my point was, doing computer stuff also keeps me occupied with what I feel I need to do. I did make a one-day-at-a-time vow against my inane computer/phone game, which I've kept to for ten or so days so far.

I wish I could explain the states I've been in. My body has been so at peace it doesn't want to move, especially since moving often evokes a coughing fit. And a soup of swirling images. A sound-bite will merge

into something visual, to a memory flash from yesterday, to something that might happen tomorrow, to a scene from a TV show I haven't seen in a month. With my eyes closed I'll see an image of somewhere I went in Spain, realize I'm lying in bed thinking of thinking of what to do next, then wake up (an exaggeration), wonder is it a time to take a pill?, yes it is, then I doze off, wake up two hours later with the pill still in my hand ... I tried dictating this once before but, lost it due to different devices overwriting each other. Both Kathy and Paulette are coming to visit this month. It's hard for me to think. A lot of times I am looking at something, not really looking at anything.

A couple of weeks ago several people came over with some great lunches! I updated my food tab if you are thinking about that – simple things that are easy for me to digest. I seem to be winding down on that though, perhaps because I am so occupied with maintaining my body – dealing with pain, or other issues that arise, coughing, aches, etc. Talking can also be a strain because it makes me cough more. Yesterday I was talking to Danamaya and counted four times that I forgot the second half of a sentence. (Thankfully I can always find it again, so far.)

Helen is dropping by some muffins. I may be seeing Misha tomorrow.

OK, I better write the rest in another post!

September 20: **What she sees is quite lovely**

From Padmatara: Things are changing fast for Suvarnaprabha. She has asked not to have visitors for a while – she loves to see her friends but it is very tiring. She seems to be doing what the books tell us she will, going more inward. She sometimes sees things – they call it visioning and it's pretty common – and what she sees is quite lovely: beautiful trees on the ceiling, a bridge with her and her friends looking down at her – that kind of thing. She can still talk beautifully but it is hard for her to think and speak about anything that isn't happening right now. It is very important for her to get this blog published, but it's unlikely she will contribute much more herself. Candradasa and Vidyadevi are working on it.

The hospice nurse visited yesterday, and some of you know or guessed this already, but it seems the difficulty speaking and thinking is not the result of taking morphine, but just the disease progressing, fatigue, and the natural dying process. She has very little appetite, just a bite or two of food now and then.

She is surrounded by her family and, as has been said many times, more love than it's possible to imagine. She knows you all love her and she loves you back.

September 21: **Curious and surprised**

Suvarnaprabha seems more and more in her own world, commenting on things that we can't see (though I wish we could). It is increasingly hard for her to communicate. She seems curious and surprised, but

not particularly worried by this. She needs a lot more help as time goes on, mostly from her gentle sisters, and she accepts it now with grace and humor (mostly).

Some people at the Buddhist Center will be organizing meditation and chanting at various times in the next few days – I'll post the information here.

Take care of yourselves and each other.

September 22: **Crazy dreams**

Things were different again this morning – wide awake and talking a lot. Thought I'd share a snippet as best I can.

I had crazy dreams, not creepy ones, crazy – I was dreaming – I was at the seaside – but I wasn't sure if the musicians were real. Ivor Cutler. I'm not sure whether – I suppose it doesn't matter where they're coming from or going at this point.

September 23: **Much quieter**

After a couple of days of being wide awake and commenting on everything she saw, Suvarnaprabha became much quieter yesterday afternoon, and more sleepy, and now this morning she is hardly communicating at all. She is very weak and can't swallow food.

Laura arrives back tonight, so the four sisters will be together for a little while.

September 24: **Transition**

Dear friends of Suvarnaprabha,

Suvarnaprabha died at home, with her sisters, Julie and Padmatara right by her. She was conscious right up through yesterday. Our hearts go out to all those who are grieving.

The Center is commencing a 24 hour program of collective practice to support Suvarnaprabha and her community of friends and family in this transition.

Tomorrow, Sep. 25, starting at 6:30 in the morning we will begin an hourly cycle of practice that will end with our sangha night class.

You can arrive at the beginning of each hour of practice, in the morning 6:30am, 7:30, 8:30, and so on through the day up to 5:30pm. We'll end with sangha night together from 7-9pm and a final transference of merits. We will practice straight through the day and imagine people joining us in places near and far.

As there is more news of memorial arrangements we will let you know. Suvarnaprabha has been and is now, beyond description.

September 25: **Woman extraordinaire**

Dear Friends,

We are planning to come together to help each other say good bye to our dear friend, sister, mentor, and woman extraordinaire, Suvarnaprabha.

Please join us on Friday, Sept. 27th from 1pm-3pm at **Fernwood Cemetery, Mill Valley.**

(Walking shoes will be helpful as we are walking to her plot up a hill. Leave your Jimmy Choos behind is what we're saying!)

If you would like to bring a flower to place on her grave, please do.

The Buddhist Center doors will be open to welcome all of you who would like to gather after the service.

*

The Bodhisattva's New Shoes

11 October 2010

Mark these words cabrones:

I will come back again and again
and loving dogs will chase me
yapping and jumping.

I'll come not in a saffron robe
but in boots made from
car tires, recycled titanium
and a cowboy hat when
it's raining.

Not clinging but singing
(a virtual Julie Andrews twirling on a hill)
straddling
a bike with leaking fork seals
(Europe and Asia's waited-for
beginner mind)
(and loving dogs will chase me)

The occupants of this this this
world however it is will be my
lovers the pigs the birds

hedgehogs foxes bald

people in hospitals devas

Anonymous Sex and Love Addicts

whispering behind walls

Todo el mundo sera mi amante, señores
and I won't try to teach it anything, ever,
(I will only love it)
(a howler monkey in Dolby)
(the vibrations of joy from my laughter
will soothe the psychoanalysts in the hell realms)

A gentle kiss
pure love steaming out the front end
of a vehicle
which is the unadorned body
the soft strong body
(think of loving dogs)

like this
like steam, like the sweet smoke of a
Cuban cigar, radiating up, sinking down,
in this this this world
returning again
coming back
forever

Recordings by Suvarnaprabha

1. A recording of Suvarnaprabha speaking from her last retreat about becoming an Anagarika within the context of the Triratna Buddhist Order: someone who commits herself fully to a life of stillness, simplicity, contentment and celibacy. Here she speaks candidly and movingly about her reasons for that and what draws her to make such a declaration in the face of her own mortality.
2. Community Memorial Singalong for Suvarnaprabha
3. Cancer and the Preciousness of Life
4. [Talks on Buddhism by Suvarnaprabha](#)

Cover Photo:
From Crap! ve Gas! Cancer
Monday, September 17 2012
Author Photo:
Dayanandra

'If you have already been strapped into that very particular roller coaster that is cancer – and if you have not – my wish is that this book will both entertain you and help you to understand more deeply and appreciate more fully the miracle that is your life.'

