

Below are emails that I sent to family and friends, documenting my journey through cancer.

Bad News 4/20/08

I don't know how to say this except to come right out with it - I have cancer.

It's rectal cancer, stage II (penetrated through the rectal wall but no lymph nodes involved and no metastasis) so my chances of surviving it are pretty good - around 85%. I had a routine screening colonoscopy 3 1/2 weeks ago, and they found a big, ugly tumor (I have PICTURES!). A week later I had an endoscopic ultrasound, which confirmed cancer. Then my first visit with an oncologist, to plan my treatment. Then a CT scan to see if it has spread - it hasn't. Then my first visit with the radiation oncologist, to explain the radiation treatments.

I will have daily radiation treatments plus chemotherapy, to shrink the tumor, for about 5 weeks starting around May 1, then wait about 6 weeks for me to recover from the treatment, then surgery.

This week on Wednesday I go for a radiation "simulation" in which they do a bunch of different scans to locate the tumor precisely in order to program the radiation machine. On Thursday I have my first consult with the surgeon, and my second visit with the oncologist, Dr Tai, to firm up the plan and go over the details of chemo.

I'm very lucky in my medical team - first that they are really functioning as a team. They have a "tumor committee" meeting on Fridays, and when they discussed my case the gastroenterologist who did the colonoscopy was there, as was the pathologist who read the biopsy samples, plus my oncologist, and the surgeon. So I don't feel any need for a second opinion - I feel like there are already a lot of opinions involved. Second, I have been treated with respect by every doctor I've talked to (which isn't always the case).

I'm also going to two cancer support groups, which I'm finding very helpful. I get support, acceptance, encouragement, and practical tips and ideas. Plus it's the one place where I feel free to obsess about cancer as much as I need to. My friends & family have been supportive, but I know there's only so much cancer talk that they can take before they have had enough of the subject.

I've started lining up helpers who will each drive me to treatments one day a week, if/when I get too sick from the chemo to drive myself. Everyone has been very supportive and encouraging, and I feel very cared for.

If you believe in prayer, please pray that the radiation & chemo will make the tumor go away completely. It's not the most likely outcome, but it is a significant possibility.

Health update #2 4/25/08

Family and friends –

First, if you haven't had a colonoscopy, PLEASE have it done. It isn't just for the purpose of detecting cancer - during the procedure the doctor will remove any polyps he finds, thus preventing possible future cancers.

Second, I have read several places that cancer correlates strongly with obesity and a low level of exercise. So if you are fat and sedentary like me, please get up and start moving.

Now for my week.

On Wednesday I had the simulation for the radiation treatments - and hour and a half of lying perfectly still, face down on a hard table, with my arms reached straight over my head. My shoulders ached by the time it was done. They want to target the radiation as closely as they can to the tumor, so they kept running me and the table through a scanner, then making little adjustments to my position, then running me through the scanner again. When they finally got a scan that the doctor (Dr Ray) liked, they made 4 little black tattoos on my sides and back which they will use for positioning me during the treatments and aiming the radiation beam.

On Thursday morning I had my first appointment with the surgeon, Dr See-Tho. I really liked him, but I got a big surprise. On the CT scan he found a problem in my appendix - not cancer but a stone and some fluid build-up. He's concerned that it could get infected during the radiation & chemotherapy treatments, when my immune system is compromised, so he recommended taking out my appendix before starting the treatments. He called the oncologist (Dr Tai) who agreed - he doesn't want to have to stop the treatments in the middle for an appendectomy, because the treatments are less effective if they are interrupted.

So I'm having outpatient surgery for an appendectomy next Tuesday, during which the surgeon will also install the port for the chemo treatments (to save wear & tear on my veins, which are small & deep and hard to find). The schedule for the radiation & chemo has been pushed back a week - which is probably a good thing, as I am teaching a class for the genealogy society on May 3, and was a little concerned about teaching after starting chemo. As of now I don't have any other commitments until jury duty the first week of July.

I also discussed surgical options with Dr See-Tho, and he recommended that I get a second opinion. The medical group added a colorectal surgeon a year ago, and I have an appointment with her next Monday. Dr See-Tho said I need to see her before I start the radiation & chemo, even though the tumor surgery won't be until the end of July or so.

On Thursday afternoon I had my second appointment with Dr Tai, the oncologist, during which I got the details of the treatment schedule. The radiation treatments will be 5 days a week for 6 weeks. The chemo schedule will be three 2-week cycles. On the day of the first radiation treatment I will go in for an infusion of Oxaliplatin, which goes in through the port and takes about 2 hours. They will give me Xeloda, which comes in pills, to take for 7 days. Then 7 days with no chemo (but the radiation treatments continue). Then the 14-day chemo cycle starts again.. The treatments will end around the middle of June, when they will re-assess the tumor and schedule surgery for about 6 weeks later.

I continue to be very pleased with the way that my doctors work together as a team.

I've been going to support groups on Tuesday & Wednesday afternoon, which help a lot (except I missed the Tuesday group this week because I spent the entire day dealing with car repairs - arrrgghh!). Next week I start an exercise program for cancer patients on Monday & Wednesday afternoon - which conflicts with the Wednesday support group so I will miss that for a while.

My schedule is so full of cancer stuff - I don't know how anyone continues to work while they are dealing with all this. I know that later on I will probably be unable to work due to the debilitating effects of the chemo - but right now I just don't have time for it. Maybe being out of work is a blessing.

Speaking of debilitating - I now have 5 helpers to take me to daily treatments if/when I am unable to drive myself. I also get 2 or 3 phone calls each day from people offering help or just being there for me. I feel very cared for.

Health update #3 5/4/08

Friends & family –

This week was mostly pretty quiet. I had surgery on Tuesday, and recovering from surgery is about as much fun as watching paint dry. It was outpatient surgery - laparoscopic appendectomy and installation of a port for chemo - and I went home late Tuesday afternoon.

Monday morning I had a consult with a specialist for a second opinion about the surgery for the tumor. That surgery is about 3 months away, but Dr See-Tho said I need to see the other surgeon now, before the radiation & chemo change things. The second opinion was not encouraging. The standard surgery for a tumor as low as mine is to remove the entire rectum, route the end of the colon through an opening in the abdomen, and wear a bag for the rest of your life to collect the output (ick!) I was hoping that the specialist would give me some other options, but no such luck.

Monday afternoon I went to the first session of an exercise class for cancer patients at the YMCA, co-sponsored by Stanford Hospital. It was nice, about 15 people of varying ages and fitness levels (translation: I wasn't the only fat, sedentary old lady). The exercise is individually paced, and I can attend as I am able over the next 12 weeks.

Next week is really busy - I have a consult on Tuesday with the oncologist's nurse to discuss chemo side-effects and how to deal with them, and to schedule the first chemo treatment - probably for Wednesday or Thursday. I have appointments for radiation treatments Wed, Thurs, & Fri. Plus exercise class on Mon & Wed, and support group on Tuesday. This thing has really taken over my life!

I continue to feel very well cared for. Ann told me I have to let people take care of me, Nancy brought me home from the hospital on Tuesday, Leanne took me to Longs to pick up some things on Wednesday, and Bob took me back to the hospital on Friday to pick up my car. (I met Ann 9 years ago at Al-anon, I met Nancy at the genealogy society, I met Leanne 30 years ago when our sons were in preschool together, and Bob is my next door neighbor). I have 5 helpers lined up to take me to daily radiation treatments if and when the chemo makes me so sick that I can't drive (I expect that to happen during the second round of chemo, in about 3 weeks, or the third round, in five weeks).

Thank you for your continuing prayers and good wishes.

Health update #4 5/11/08

Friends & family –

It's been an intense week: 6 medical appointments, plus exercise class, support group, and an Al-anon meeting.

I'm going to divide the events up into categories.

TREATMENT

I had my first radiation treatment on Thursday. The actual treatments are pretty easy - only 20 minutes - a nice contrast to the long times that I had to spend stretched out on a hard table with my shoulders aching for the simulation, 1 1/2 hours, and the set-up appointment, 1 hr 15 minutes. No side effects so far.

I had my first chemo infusion on Friday - 3 hours sitting in a chair. I, of course, took my current book and just read the whole time. The first part of the treatment was the drugs to control side-effects, especially nausea; then 2 hours for the actual chemo drug.

I'm taking 2 drugs, Oxaliplatin, which is delivered by infusion through a port installed just below my collarbone, and Xeloda, which comes in pills. I was supposed to pick up the Xeloda at the pharmacy and start taking it Friday morning, but I just plain forgot. I'm overwhelmed by all the details right now, and hadn't actually written that one down - so it didn't happen. So I started it in the evening instead - more details below, under "frustrations".

So far I have experienced 3 side-effects from the chemo - first was cold sensitivity, which I had expected. It had been suggested to use gloves to get things from the refrigerator, and I needed them - it stung when I touched a jar in the refrigerator Friday night. The cold sensitivity is in my hands & mouth, as expected, so I'm off cold foods for the time being. But I was prepared and stocked up on warm or room-temperature foods & drinks.

Second was nausea - so far it's very mild, just a little queasiness - but I can feel the anti-nausea drugs fighting with the chemo drugs. So I mostly just eat a little bit at a time.

Third side-effect is low energy and insomnia - but right now I don't have to do anything but take care of myself. So that's okay.

Basically I'm all right, able to drive and do the things that need to be done. Bob M drove me from chemo to radiation on Friday, because I wasn't sure exactly what sort of reaction I might have to the first chemo, and it turned out to be a good thing, I was a little shaky. But after the radiation he took me back to my car and I was okay to drive.

GOOD THINGS

Exercise class, Monday & Wed afternoons. Designed for cancer patients, which means a very gentle pace, and a "we're all in this together" feeling. I came out of the class feeling great - partly from "I can do this" and partly because it's something I'm doing for me, it's not just about the cancer like everything else on my schedule.

Appointment with the oncology care coordinator - a nurse named Kathy who does a lot of patient education & hand-holding. She was wonderful! She spent more than an hour with me, laying out the details of the treatment plan, telling me what to expect, how to deal with the side-effects, who to contact in emergency (and what exactly constitutes an emergency). She made me a beautiful color-coded calendar showing all my treatments, which days to take which drugs, appointments to track my progress, blood tests before each infusion - so many details!! but she made them all clear.

My helpers, who have been giving me rides and support as needed. I'm still feeling very private about the whole thing and haven't told very many people at the genealogy society or at Al-anon - but I told another member of the genealogy society on Saturday, and immediately acquired another driver. I feel so very well cared-for! And ongoing thanks to Ann, who tells me that I need to let people take care of me!

FRUSTRATIONS

I have made a point of scheduling things at least an hour apart, because the oncology, surgeon and chemo treatments are in Mountain View at the Camino Medical Group clinic, the radiation is at the Palo Alto clinic, the exercise class is at the Y in Cupertino, and the support group is in Mountain View at El Camino Hospital.

But on Wednesday - the setup for the radiation was supposed to take 1 hour, but they ran over by an extra half-hour. Since I had allowed an hour between events, it should have been okay, except that it ran into rush-hour traffic, so I was 1/2 hour late for the exercise class.

Also on Wednesday the surgeon was 35 minutes late for the follow-up appointment for the appendectomy and port installation last week. He's chronic - he was even late to the surgery, and one of the nurses said he's always late.

On Friday, the chemo treatment was supposed to be 3 hours, from 10:30 to 1:30, and I had radiation at 2:30. Plenty of time. Except the the chemo went over by about 15 minutes and then I had to make a bunch of appointments and the receptionist's phone kept ringing. But Bob was very calm and patient and we got to the radiation appointment on time.

Worst of all was forgetting to pick up the Xeloda - because when I got to the pharmacy on Friday after the radiation treatment, they hadn't gotten the necessary approval from my insurance. I haven't had any prescriptions for a long time so their info for me was out of date, and they never called me to update it. By then it was 4 pm - too late to get the problem fixed. I picked up the anti-nausea pills, but the chemo drugs are EXTREMELY expensive. And I was in a panic, because the radiation and the 2 chemo drugs were all supposed to start at the same time, and it was starting to look like there would be a delay until Monday or Tuesday for the Xeloda (why do these things always seem to happen late on Friday?). But it turned out okay - see "more good things" below.

MORE GOOD THINGS

When I got home from the pharmacy, all frazzled and frustrated, there was a beautiful arrangement of purple, pink & white flowers on my door-step from Ryan & Amy for Mother's Day. What wonderful timing!

Then I called Kathy, the oncology care coordinator. It was an hour and a half before she called back, but she took care of the problem - she had a bottle of the Xeloda pills made up for me and took it over to the urgent care center so I could pick it up after hours. So I was able to start the Xeloda on Friday night after all.

On Saturday night I went to my regular Al-anon meeting. I haven't been to many meetings lately - partly because there have been too many other things going on, and partly because I'm not ready to share openly in a large group. But the meeting was much smaller than usual - only 6 people - so I felt comfortable talking about it, and that felt good.

Although I'm having to deal with side effects, I think I'm relieved to have finally started the treatments. All the waiting was wearing me down. During the radiation treatments and when I'm aware of the chemo making me queasy, I just keep thinking "kill it kill it kill it!"

Thank you for your continuing prayers and good wishes.

Health update #5 5/11/08

Family & friends –

Well, I've made it through my first round of chemo. Two more to go (at least).

I took the last pills on Friday and expected to start feeling better within a day or so. But it turns out there's a delay before the side effects kick in, and a delay before they go away. Today (Tuesday) is the first day that I've felt a little better - and I expect my energy to give out mid-morning as it has been doing every day. I discussed it with Ann and she said the same thing - she didn't really feel better until the last day or two before the next round.

Side effects: the nausea was mostly kept under control by meds, but my stomach is still very sensitive and I'm eating very small amounts at a time. Diarrhea developed in the middle of the week - kept under control with Imodium, plus the radiation nurse gave me two pages of details about a "diarrhea diet", which excluded almost everything I had been eating and required a trip to the grocery store for all new supplies. Fatigue is the other most frequently experienced side effect, but the word "fatigue" doesn't do it justice. Picture something more along the lines of being flattened by a steam roller. I've been spending a lot of time lying on the couch with my eyes closed - don't even have enough energy to watch TV.

Summary: sensitive tummy + sensitive gut + steam-roller-effect = generally pretty icky, but tolerable.

The one big surprise in the side effect department was insomnia. It started Saturday night, the day after the first chemo treatment. That night I only slept 4 hours plus a 2 hour nap; Sun & Mon night 3 hrs each and I tried to nap but couldn't sleep; Tues night 2 hours and no nap. By the middle of the night on Tues I was feeling sick with exhaustion, almost in tears. (I now understand keeping people awake as a means of torture.) I talked to my oncologist, Dr Tai, Wed morning and he was surprised by it, wanted to ascribe the insomnia to anxiety over the treatment. I told him I know what anxiety feels like, this isn't it. This feels chemical, like being hopped up on caffeine during final exams in college. I also pointed out that insomnia is on the list of side effects from Xeloda, but apparently he hasn't run into this before. Anyway, he gave me a prescription for Ambien, so now that side effect is under control too - more or less. Afterward I discussed it with the radiation oncologist and he said the same thing - anxiety about the treatment; I said the same thing, and he looked dubious - just like Dr Tai. Then Ann looked it up on the internet and found that in the clinical trials for Xeloda, 8% of people reported insomnia. So it's not just me - hah!

I'm starting to understand the balance between side effects and treatment - the goal is to keep the side effects under control just enough that the patient can get through the treatment. Sometimes the treatment has to be reduced or even interrupted because the patient can't tolerate the side effects, but that makes the treatment less effective. So the doctors want to keep the treatment going and will do whatever they can to ease the side effects and make them tolerable. Thus a prescription for Ambien, even though he was doubtful about the exact cause of the insomnia.

I skipped the exercise class Wed & Mon; skipped Al-anon Saturday night, printed the mailing labels for the genealogy society but skipped lunch with the group afterward; went to the genealogy society board meeting but skipped the homeowners assoc board meeting and will probably skip the Al-anon district

meeting - I'm the treasurer, but they can do without me this month. I don't know if I'll go to the cancer support group today - depends on how I feel after radiation treatment this morning and a doctor visit in the afternoon. I hope to go to the exercise class Wed - I really need it and can adapt the pace - but if I'm too weak to drive, I probably don't belong in an exercise class! I need to go grocery shopping Wed or Thursday to stock up before the next round. I need a haircut, starting to look pretty shaggy and if I don't get it done now, the next window of opportunity is 2 weeks away. Maybe Thursday, after the things that absolutely must be done have been done (like getting groceries and paying bills) - depends on how much energy I have. There's nothing as effective as illness to sort out what's essential and what's not.

This thing has completely taken over my life. My only consistent activity has been daily radiation treatments. Many thanks to my drivers: Nancy, Leanne, Bob C and Bob M.

I've been enjoying the phone calls, it's nice to keep in touch, keeps me from feeling isolated. You don't have to worry about waking me up - when I go to sleep, I unplug the phone and you'll get the answering machine. (I found that if I turn the ringer off, I forget to turn it back on, but if I disconnect the wire, I notice it after I get up and I plug it back it. So that works for me.)

Health update #5.5 5/20/08

Family & friends –

Before each round of chemo I have a checkup with either the doctor or the nurse practitioner. Today's appointment was with the nurse practitioner, and she was GREAT! She bawled me out thoroughly for putting up with the side effects and not reporting them, told me what to take for which things - especially the diarrhea, which she said can lead to dehydration and which I am to take SERIOUSLY and if not I could end up in the hospital. She said she intended to put the fear of God in me - and she was successful. (I have Imodium for the diarrhea but haven't been taking it as frequently as I should.)

She said there is no reason for me to feel miserable - which made me realize I haven't been doing everything I could about the side effects because I thought I was SUPPOSED to feel miserable! I think with her help, the second round of chemo might be easier than the first.

It was a very interesting visit.

I feel much better today than I have for a while - not good, exactly, but definitely better. After the appointment with the nurse I went to the grocery store and stocked up for the second round of chemo, which starts Friday. By the time I finished at the store I was starting to fade, so I came home and took a nap.

Health update #6 5/26/08

Family & friends –

Last week was my off week from chemo. The side effects from the previous week's treatments started to fade a little on Tuesday, and on Wednesday, Thursday, and most of Friday I felt pretty good, but not a lot of stamina so I paced myself carefully and took frequent naps. I still had daily radiation treatments, went to exercise class on Wed and took a couple of short walks on Thursday.

Friday was a full day - started off very well but ended up pretty awful. I drove myself to radiation treatment, then to the Y to go through my exercise routine. The class is on Mon & Wed, but I've decided to also go in on Friday when I'm able, in order to improve my stamina. Then a small lunch, then to chemo - a 3-hour infusion of Oxaliplatin plus anti-nausea meds.

So far so good - but when I left after the chemo treatment I discovered that I'd left my keys in my car. I never do that!. I ALWAYS check my right-hand pants pocket for my keys before I lock my door!!! (And I don't buy pants that don't have pockets!) But this time I didn't check - probably because I was busy checking for all the things that I had to take in for the chemo - a book to read, a spare book in case I finish the first one, my water bottle, crackers, the lab sheet to make the next set of appointments, the calendar that the Care Coordinator gave me, my 2 binders of info, plus taking along a certain amount of anxiety - so maybe it's not surprising that I missed the keys.

I used the oncology clinic phone to call AAA and gave the dispatcher ALL the info, of course - the address, the clinic name on the building, which driveway into the lower level of the parking structure from which street -- everything. And all he passed on to the driver was the name of the street and to go in the driveway -- didn't mention the clinic, the building address or the parking structure - and on the other side of the street is a large apartment complex with a gazillion driveways. So the driver wasted about a half hour investigating all those driveways - but he didn't give up and he finally found me and got my car unlocked for me. (I called AAA the next day and registered a complaint against the dispatcher)

My next activity was game night - Trivial Pursuit - at Nancy's house, which I really enjoy and was not going to miss if at all possible. I was about 40 minutes late so Nancy & Lynn were worried, because I'm always on time. So the first thing I said when I got there was that Nancy gets to say "I told you so" because she keeps saying I need a cell phone. And she was right - if I'd had a cell phone, the driver could have called me and located me much sooner, and I could have called Nancy & Lynn and told them not to worry. So Nancy is researching ways to get me a cheap cell phone plan - possibly one that's designed mainly for emergencies and doesn't have high charges and a lot of talk minutes.

I enjoyed Trivial Pursuit for as long as it lasted. Lynn brought along a new player, Patty, who fit in very well with the group. (We've been down to only 3 players since Marilyn moved to Sacramento and Sue moved to Arizona) During the game I started shaking. A little shaking is normal for me - I have essential tremor which I inherited from Pop, who got it from his mother, who got it from her mother - and it gets worse at times of stress or when I'm feeling tired or weak. But this gradually got pretty violent - so bad that I couldn't talk unless I clenched my teeth. So Lynn drove me home in my car, and Nancy came in her car to take Lynn back, and Lynn said to call her at Nancy's after I talk to the doctor. I called the doctor and left a message and he called right back - it turned out that the doctor on call was my oncologist, Dr Tai. I was still shaking badly, didn't feel chills but temp was up to 100.6 He told me to take Tylenol, and called in a prescription for antibiotics - he knew exactly which local pharmacy is open 24 hours. So I called the pharmacy and gave them my insurance info and they got the approval, and I called Lynn who picked it up and brought it to me. By then the temp was up to 102.4. I was cold and sweaty all night, but by morning the temp was down to 100.6, and by afternoon it was gone. With a few phone calls and help from some good people, a possibly difficult situation was made easy for me.

I hope Patty doesn't see this as a bad omen, and that she'll return and play Trivial Pursuit with us next month.

I don't know if the fever was a reaction to the chemo treatment or if it was an infection that had been building up and the fact that it showed up on the same day as the treatment was just a coincidence. The

doctor's theory is that that the infection is in the tumor, which is breaking down and therefore is an open wound.

But once again I feel very well cared for by my friends and by my medical team. All I have to do is ask for help and be willing to accept it.

My side effects from this round of treatment are a little different from last time.

Last time I had serious pins-and-needles in my hands, but it only lasted an hour and then didn't return. This time the pins-and-needles is milder but hasn't gone away, and is also in my feet and in my legs up to my knees. Not a problem, just different. I also have some cold sensitivity in my hands & mouth like last time, but again it's a little bit milder, and not really a problem - I have kept my knitted gloves next to the refrigerator. Only new problem in my hands is sensitivity to pressure in my fingertips, which makes it hard to open bottles (and I've got a TON of pill bottles) and kind of hard to type on the keyboard. I have insomnia, queasiness, & diarrhea like last time, but all are under better control - partly because this time I have all the necessary meds, and partly because this time I'm actually TAKING the meds when I should. I'm feeling generally a little worse than I did at this point last time, but I don't know if that's due to the chemo or just recuperating from the fever. I was hoping to go to the Y today but don't feel up to it - I'll probably just take a few short walks in between naps.

Beth came over for a visit yesterday. She's been feeling anxious about me but has been very busy, preparing for not one but two art shows, so finding a day when she was available and I was feeling well enough for company has been difficult. But we finally worked it out. We had a nice talk and filled each other in on what's going on in our lives, then went out for a little lunch, then she took me to the grocery store for some things I was getting low on, then we came back and talked some more, and then I started to fade and needed a nap. It was great to see her; I think it was reassuring for both of us, including being able to talk about Pop - his birthday is tomorrow, the second one since he's been gone.

I think this round will be easier, mainly because there aren't so many unknowns. I know what to expect from the meds, I know that I can get help from my medical team when I need it, I know that I can get help from my friends when I need it, and I know that I am capable of accepting all that help - which may be the most difficult part for me. And I know that in about 8 days I will feel good again for a few days - before the next round.

Beth - I'm wearing the purple shirt - very comfy indeed.

Kathy S - please print a copy of this for your Mom - unless she has finally gotten email?

Jay - thank you for making me laugh

Bob, Bob, Nancy, Leanne, & Lynn - thank you for rides and courier service, any time of the day or night.

Ann - thank you for being available to talk about EVERYTHING!!!

And thank all of you for your continuing prayers and good wishes. Please don't hesitate to call if you would like to chat. You don't have to fear that you'll wake me up, because I disconnect the phone when I go to sleep, so you'll get the answering machine and not wake me up. And the phone calls help to keep me from feeling isolated.

Health update #7 6/5/08

Family & Friends –

A week ago, Thursday 5/29, was the last day of my second round of chemo. Tomorrow I start the third round. This afternoon I have my regular between-rounds check-in appointment with my oncologist, when I'll find out the details of the chemo schedule going forward (the calendar I was given only shows dates through next week.) I'm continuing daily radiation treatments - but only for one more week! Hoorah!!! There have been some surprises during my current "off-chemo" week, the biggest being that I recovered from chemo MUCH faster than after the first round. The first round ended on a Thursday and it took until the following Tuesday afternoon before I started feeling human again - about 5 days. And I never did really get my energy back before starting the second round. (Human as opposed to what? I'll tell you about that later.)

This time I started feeling better on Saturday afternoon - only 2 days instead of 5. Wow! I discussed it with my friend Ann, who has been through this and is interested in all the clinical details (she's also a little strange - what can I say). We talked about the things that were different in the second round, and the most significant seemed to us to be that Joanna (the nurse-practitioner) had been VERY FIRM with me about keeping the diarrhea under control, with the result that I took Imodium AD EVERY time I was supposed during the second round instead of only a couple of times a day during the first round. We think that the fatigue I continued to feel after the first round was due to loss of electrolytes rather than due to the chemo.

But for whatever reason, I feel like I've received a little present: 3 days of my life that I got to enjoy instead of lying around feeling miserable - double WOW! And even better, my energy level has continued to rise. And I've turned into Motor Mouth! I can't seem to stop talking - all this energy just keeps coming out in words. Also I've been to the library to bring the genealogy society membership records up to date; I've been to 2 bookstores and the grocery store, and to the gen society's bank to sign signature cards, and to an Al-anon meeting (haven't been for a while), and to my exercise class on both Mon & Wed, and to cancer support group on Tues, and drove myself to radiation starting Tuesday, and attended the finance committee meeting for my homeowners association which I haven't been to for about 3 years, ... See what I mean - Motor Mouth!

I called Joanna on Tuesday and thanked her for being so FIRM!! (one of the things she said was that she was going to put the fear of God in me. Yay Joanna!)

Tomorrow I start the next round - but it will be easier knowing that the down part will only last a week instead of 10 days or more.

Now back to "human as opposed to what?" One of the side effects of chemo is something that the doctors refer to as "fatigue" - but we all know how doctors like euphemisms. "Fatigue" just doesn't cover it. Part of it is lying on the couch without even enough energy to watch TV, much less read a book. And "fatigue" implies that you just need a little bit more sleep. Nope. So for a while I was using the term "flattened-by-a-steamroller syndrome", which all my cancer survivor friends feel is much more accurate. But it doesn't include the "icky" factor, so I continued to search for a better term. I finally came up with "mud puddle" - which still isn't exactly right but is a LOT closer than "fatigue". Think about it - a mud puddle is all horizontal, no vertical energy or structure at all. You can picture it lying on the couch without enough energy to even watch TV. And it includes the "icky" factor, too.

I am accepting nominations for a better term, but for now - this week I'm feeling like a human being instead of a mud puddle.

I'm attaching an article by Dave Barry about his colonoscopy experience - optional reading, but it's hilarious (of course - what else do you expect from Dave Barry). I saved it as a text file to make it small, for the benefit of those of us who still have dial-up internet access.

(By the way, I am NOT excited about the fact that I have used the word "diarrhea" so many times in the past few weeks that I have finally learned to spell it correctly without having to look it up.)

Health update #7.5 6/6/08

Friends & Family –

At my visit yesterday afternoon with the oncologist, Dr. Tai, he laid out the plan for the next month or so.

Today I start the next round of chemo, which ends next Thursday, the same day as the final radiation treatment. (This means I'm entering 8 or 9 days of ickiness, so don't expect to hear a lot from me. But also remember that I disconnect the phone when I take a nap, so it's okay to call - you won't wake me up.)

Then a week off; then one more round of chemo.

Then wait a week or two, then an ultrasound examination to re-assess the tumor. (This has to wait a month or so after the end of the radiation treatments, for me to heal inside)

Then there are 3 possibilities:

- 1) the tumor is gone. Wait a few weeks then minor surgery: an excision to remove the scars and underlying tissue from where the tumor was and examine it, to make sure there's no cancer left. For me, this is the best possible outcome.
- 2) the tumor is radically reduced - the treatment is working but we need to continue chemo for a few months longer, then do the excision..
- 3) the tumor is only slightly reduced, so the treatment has only been minimally effective, and we need to consider other treatment options, which may be more effective but also have more serious & possibly permanent effects.

I don't believe that 3) above is true in my case, because I'm having a lot of bleeding and passing clots, which the doctors tell me is from the tumor breaking down.

An excision is similar to a lumpectomy where they just cut out the affected material, as opposed to a resection where they remove the rectum. Resection is the "standard of care" even after a tumor is reduced completely by radiation & chemo, mainly because the design of the treatment is driven completely by the statistics on recurrence of cancer. There are no statistics on not having resection surgery after completely reducing the tumor, because nobody does it that way,

because there are no statistics,

because nobody does it that way,

because there are no statistics ...

(Note: there are some variations on the type of resection, but I'm trying not to wander too much into the technical details)

I think the reason why resection surgery is always done is because for many years the surgery was the main treatment, with chemo and possibly radiation just to clean up any cancer cells that escaped. As new chemo drugs have been developed and the whole chemo regimen has been more customized to specific

cancers and made more effective; and as radiation treatment has undergone similar changes; a shift is taking place in which the chemo and radiation are becoming the main focus of the treatment with the surgery gradually taking second place. All of the doctors and nurses that I've had time to chat with are really excited by the changes going on in their field, by the advances that have been made in treating the cancer and also in taking care of the patient so that the treatments are better tolerated (like better anti-nausea medications). They also have been open about the fact that the changes are continuing and that the new treatments that seem so advanced right now will probably look primitive just a few years in the future.

I'm very impressed by the respect that my oncologist has shown me, in taking my feelings about the resection into account and designing the treatment around that. He even went so far as to say that it's possible that in the future, an excision may become the "standard of care" when a tumor has been completely reduced - but right now there is no data to support it. His respect for my feelings and willingness to consider and discuss options is very different from the experience of some other cancer patients I've heard from, and I feel VERY lucky in my medical team and especially Dr. Tai.

I've also decided that with this particular doctor, it's a good thing to have the last appointment of the day. He gets very chatty when he doesn't have other patients waiting, and I get a lot of info that I might not otherwise learn.

Thanks for your love, prayers, and good thoughts. And if you don't feel that you can send prayers, then send thoughts of "kill it kill it kill it!"

Health update #8 6/20/08

Family & Friends -

It's been 2 weeks since I wrote, longer than I intended. I have 2 excuses - first because I have felt so icky, and second, there hasn't been much to say since I felt too icky to do very much.

On Monday 6/9 I went to the YMCA exercise class even though I didn't feel up to participating, because the class had visitors from Idaho who are working on setting up a similar program, and I wanted to talk to them. It turned out to be well worth doing - they had all kinds of questions about all kinds of details, including wanting to know about my cancer treatment. I told them all the things I like about the class, and stressed that they should include people who are currently in treatment - some programs don't. They asked what I would change about the class - nothing! Really! I know, I can always find something to change about anything or anybody - right? But not about this class. They asked what I would add - I said a support group, but as a separate class. If they try to make them into one program, they will lose people who only want one part or the other. As I said, it was well worth doing. And Bob C and his wife work out at the Y, so they gave me a ride and nobody had to stand around and wait for me while I put in my two cents worth.

Beth took me to support group on Tuesday 6/10, which was very special for me. She was very open about her feelings about my illness, and that with Mom & Pop both gone, I am the one life-long stable person in her life, and how scary this all is.

I went to Alanon on Saturday 6/14, and to 4 radiation treatments during the week of 6/6 - 6/12 (NO MORE RADIATION!!! YAAYYY!!!!) and to 3 medical appointments during the week of 6/13 to 6/19 (sorry, my weeks start on Friday because that's the first day of each round of chemo - see how my life is controlled by this disease?) But I skipped the other Alanon meetings, cancer support group, exercise

classes, genealogy society meetings, homeowners association meetings, and an appointment to help a friend with her computer problems (I now have 2 friends who I help with computers, plus Beth who calls and says "is this tech support?")

The second week was really disappointing because it was a non-chemo week, and during the previous non-chemo week I felt great - I had so much energy that Ann got tired of listening to me because I was so perky! And I expected the week of 6/13-6/19 to be similar. But no such luck - it was mud-puddle-syndrome all over again - not enough energy to even watch TV. It could be because for most people the side effects are cumulative and each round is usually little worse. Or it could be because of the radiation - Dr. Ray said that the last week of radiation treatment and the week after would be the worst. Or it could be both.

On Thursday I knew I felt better because I read the manual for the cell phone that Nancy gave me! She was so worried about me being out of contact in an emergency (like the night when I locked my keys in the car!) that she added me to her cell phone plan. She gave me the phone about 2 weeks ago but I haven't had the energy to learn how to use it. But yesterday I read the manual, tested it out, and entered a bunch of names in the contact list - starting with AAA emergency road service! For now I'm not going to give the number out, I'm just going to use it for emergencies. And Nancy was right - it makes me feel safer.

Today I started my 4th round of chemo. So far not too bad, except each time the pins-and-needles in my legs is a little worse and lasts longer - it never did completely go away from the last round. Same for the cold sensitivity in my hands & mouth.

Then starting 6/27 I have 2 weeks with no chemo, then on 7/16 an ultrasound to re-evaluate the tumor (no chemo that week either); then on Friday 7/25 an appointment with Dr Tai to discuss where do we go next - and no chemo that week either. Four whole weeks with no chemotherapy treatments! O frabjous joy!!! (It takes so little to make me deliriously happy.)

I am starting to feel a little isolated - until last week I had daily contact with people because of the radiation treatments. I definitely don't miss the radiation and its side-effects, but I am missing the contact with people. Please don't think that you might wake me up if you call - when I sleep on the couch in the living room, I disconnect the phone wire and the answering machine picks up the call; and I turned off the bell on the phone in the bedroom and if I'm asleep in there I can't hear the bell in the living room. So it's all covered and you don't have to worry about waking me up.

Looks like I had more to say than I thought. And I think I left something out. Oh well.

Thanks for all your prayers & good wishes.

Health Update #9 7/4/08

My last round of chemo ended a week ago and my last radiation was 3 weeks ago, and I was hoping that by now I'd be able to say I was feeling great. Not!

I do see progress but it's so slow that it doesn't show from day to day - I have to look back several days to see it. I have designed a fatigue/energy scale of zero to 10, where zero is comatose and 10 is like those few days about 5 weeks ago when I had so much energy that I couldn't stop talking (Ann said I was "perky"). Right now I'm at about a 4. So - not very good, but not really bad either. A 4 means that I can go

out and do errands on my own, I can go other places and enjoy myself for as much as 3 or 4 hours before I fade and need to take another nap - believe me, 4 hours is progress! But the slowness of the progress is disappointing - I was hoping that after a full week without treatment I would be pretty much back to a normal energy level. My more-experienced friends say no - this long, slow recovery is the usual thing, that the effects of the chemo are cumulative and the recovery from each round takes longer than the last one, and that the radiation took more out of me than I realized.

Other kinds of progress -

The cold sensitivity has finally faded in the past few days, so I'm starting to be able to eat cold foods again (doesn't sound like much, but try going without for a week - including no cold drinks, no cold milk on your cereal, no ice in your tea, no salads, no yogurt or ice cream, wearing gloves anytime you handle something from the refrigerator).

Still eating small meals. Tummy isn't as sensitive as she was, but not yet totally back to normal, either, But that could be a good thing - if I can stay in the habit of eating small meals, maybe that would help with my weight. (By the way, I'm down 11 pounds from when I started treatment - that's a GOOD thing!)

The pins&needles in my legs has receded VERY slowly to just my feet.

Pressure sensitivity in my finger tips is pretty much gone. (so I'm doing a little crocheting again. Those who are waiting for blankets - I haven't forgotten)

Hands are still very shaky, much more than is usual with me. This has been the case throughout the treatment but I don't know if I've mentioned it before. This also affects the crochet projects.

No more rectal bleeding - I've thought this was gone before but it kept coming back; this time it's been long enough that I think I might really be done with it.

Diarrhea has greatly decreased - but I still need to make sure I'm near a bathroom for an hour or two after I eat.

Still having sleep problems - I've tried a few times to skip the Ambien, but I generally wake up after about 3 hours - so I take an Ambien and go back to sleep. I'm using fewer than when I was in active chemo and eventually I'll get away from them completely, probably when I get back to a normal activity level. I think there's a strong connection between physical activity and normal sleep.

Speaking of physical activity - I'm missed 4 sessions of the exercise class at the Y - just couldn't do it. But I went this Monday and did a VERY abbreviated workout - only 4 min on the recumbent bike, minimum number of reps on each of the 8 machines that I've been set up on, no treadmill, and didn't participate in the class workout. On Wed I still didn't do the class workout, but did a full set of reps on each machine, the bike, plus a few minutes on the treadmill. I'll try to go in on Saturday so I don't lose the little bit of progress I've made.

I had a fever again last week and again the doctor put me on antibiotics - no big deal, except it probably contributed to the slowness with which I'm recovering my energy.

Last Friday I played Trivial Pursuit with Nancy & Lynne and was okay - but Lynn gave me a ride and I was ready to go home when Lynn had to leave at 9:30. On Tuesday I went to Leanne's house for lunch and had a great time - didn't fade until about 4 hours. On Thursday I played Trivial Pursuit with some ladies from the cancer support group - we played about 2 1/2 hours, and I was getting a little low on energy but not completely wiped out. Tonight I may go across the street to watch the fireworks with Lynn's family & friends - depending on how I feel. I'm not making any firm commitments these days.

Between all these little outings and the exercise classes and daily phone calls, I haven't felt isolated this week like I did the past few weeks. I get one or two phone calls each day from various people, just to chat, and the phone calls really help. If you call & get my answering machine, I may be out but most likely I am napping and have disconnected the phone so the call goes to the answering machine.

Next week -

Monday I have a consult with a nurse about the prep for the endoscopic ultrasound which is scheduled for Wed, July 16 - the test that tells us the state of the tumor. Best possible outcome is: we killed it!

Tuesday I have a consult with another lady about my Advance Healthcare Directive. I've put in some time researching and writing this, and hope that with her help I'll be able to finalize it. Just so everyone knows - the important part is that I want my ashes scattered in Richardson Grove!

Thanks for all the phone calls & prayers - it's largely because of all your support that I'm handling this as well as I am.

Health update #11 7/25/08

Well, the news is partly good - but mostly uncertain.

Ten days ago I had an endoscopic ultrasound - which includes a visual examination of the tumor (I have pictures!), an ultrasound scan, and biopsy samples. The radiologist who did the scan said that it looked to him like the tumor had shrunk by about 40%, which he considers a good outcome.

The biopsy samples showed no cancer. That doesn't prove that there isn't any cancer - just that there isn't any where the samples were taken. But since they were taken from the same places as the previous samples which were cancerous, it's good news. Not proof, but certainly better than the opposite.

Today I had my visit with Dr Tai, my oncologist. It was frustrating to me because there is so much uncertainty. There are a lot of different kinds of scans - CT, MRI, PET, in addition to the ones I had - but although they all give some information, none of them are definitive. It turns out that the only way to be sure that there isn't any cancer is to remove all the tissue and look at it. So the most likely next step is an excision, where they remove the remaining tumor and scar tissue, down as close as they can get to the bottom of the rectal wall. If there is no cancer in the tissue removed, or only a small amount, I will have some more chemotherapy, just to make sure we got every last little bit. If there is a lot of cancer, then Dr Tai will recommend a resection and colostomy - which means that I will have a very difficult decision to make.

But before we decide on the excision, Dr Tai wants me to see the surgeon again, and he wants the tumor board to discuss my case, which will happen next Friday.

In the meanwhile, I've been feeling mildly icky - which everyone assures me is normal for only one month after treatment. I did go to the cancer support groups on Tuesday & Wednesday evenings, and played Trivial Pursuit last night - I seem to feel better in the late afternoons & evenings. I was feeling a lot worse today, but I think it might be just dehydration - I haven't been drinking enough water.

As soon as I have more news, I'll let you know.

Thanks for all your thought, prayers, and phone calls.

Update #12 8/7/08

When last heard from, I had been told by my oncologist to make an appointment with the surgeon - so I did. But the surgeon is going on vacation for 2 weeks and after that his schedule is backed up, so I couldn't get an appointment until the end of August. I made the appointment but left a message for the oncologist about the delay. He called me back and asked if it was okay if we switched to a different surgeon. I said yes, and he made the appointment for me. I've now seen the new surgeon - and we have to do the surgery right away because he's going on vacation on the 14th!

So - the surgery to remove the rest of the tumor and the scar tissue remaining after radiation treatments will be next Tuesday afternoon, Aug 12. I won't know the exact time until Monday, because the hospital doesn't schedule the afternoon surgeries until the day before (is that weird?). Because the surgery is in the afternoon, I will stay in the hospital overnight and go home Wednesday morning. I won't have any incisions so the recovery should be pretty easy. They're just going to scoop out the tumor, not cut through the rectal wall or abdomen.

Because of the location of the tumor, this is not considered the "standard" surgery. I've been advised by 4 doctors that the treatment that will give me the best odds is to remove the rectum and install a colostomy bag, which I would have to wear for the rest of my life. I have refused this option and decided to take my chances on just having the tumor removed. The surgeon has agreed to do it the way I want - but I was pretty depressed after my visit with him. Mostly I've done a good job of repressing all my feelings about this and just doing what has to be done, but every once in a while the fear breaks through. It didn't last for long, though; I came home and watched "Cash Cab" on TV and then went back to re-reading the "The Cat Who..." series - real mind candy, but it works for me.

Physically I've been feeling quite a bit better for the last week or so, going for 15-minute walks once or twice a day.

Brief update 8/13/08

This is going to be brief. I just got home from the hospital - but got almost no sleep last night for various reasons, and am still feeling the aftereffects of anesthesia, so I'm going to bed.

The surgery went fine - but the important part of course is the pathology report which will take at least a few days.

Thanks for all your prayers and support.

Debbie

health update #13 8/18/08

Family & friends –

Well, I still don't have the important info - the results of the pathology report on the tumor - but I thought you'd want to know how I'm doing.

The surgery to remove the remainder of the tumor was last Tuesday morning, and it went fine. I stayed overnight at the hospital Tuesday night, got VERY little sleep, and went home Wednesday afternoon. I slept 10 solid hours Wednesday night!

Thursday & Friday I was horizontal most of the day - watching TV or reading for an hour or two at a time, otherwise sleeping or lying down with my eyes closed.

Saturday morning I had enough energy to take a (much needed) shower - but afterward I was wiped out again, weak & shaky, and went back to horizontal. Saturday afternoon & evening I felt a little better and went for a couple of very brief walks - less than 5 minutes each.

Sunday I also went for a couple of brief walks, morning & evening. I went out to lunch with Ann and she took me back to the hospital to pick up my car - but that was all I had the stamina for: back to horizontal.

Today I went to the library to print the mailing labels for the genealogy society newsletter and then went to McDonalds for lunch - but again my stamina ran out: back to horizontal.

It seems to me that this is an awfully slow recovery, especially considering that they scooped out the tumor from the inside and I didn't have any abdominal incisions. A couple of people have told me that what really takes the time in recovery after surgery is eliminating the anesthesia from your system, and I now believe it.

Recovery is boring but I'm okay and have what I need. I'll let you know when I get the pathology report.

health update #13.5 8/20/08 - good news!

Family & friends -

I just got the pathology report from the tumor surgery which says "no evidence of residual invasive adenocarcinoma" which in English means NO CANCER!

WOW!

I think I'm in shock.

My oncologist had said initially that about 15% of these cancers are eliminated by just chemo & radiation, so that's what I was hoping for. But I've been working so hard at not thinking about it and not feeling about it that it may be a little while before it feels real to me.

I haven't talked to my oncologist about it yet. I think he may want to me have some more chemo just to improve the odds just a little bit more, and that's fine with me. It can't be nearly as hard as chemo & radiation combined.

Thanks for all your prayers - they worked!

health update #14 9/4/08

Family & friends –

I saw my oncologist this morning, and the plan is: 4 more rounds of chemo (each "round" is 4 weeks, alternating one week with chemo and one week off, then another week on and another week off). Even though there was no active cancer in the tumor that was removed, the doctor wants me to do the full 6 months of chemo to make sure there isn't any cancer in the remaining tissue - basically he wants to improve the odds. And that's okay with me.

It won't be as hard as the first 2 months because I won't be having daily radiation treatments at the same time.

It starts in about 3 weeks - I don't have the exact date yet. But if it starts near the end of Sept and goes for four 4-week rounds, that means it will end about the middle of January.

I still don't have much stamina, have to pace myself carefully and take a 30-60 minute rest a couple of times a day, but I'm starting to feel some improvement. The doctor said the fatigue is due to the previous chemo & radiation more than from the surgery, and is pretty standard, given how aggressive the treatment was and the length of time since the treatment ended. The 3-week delay before more chemo is to give me some more time to recover before I start treatment again.

I'm still going to a support group on Wed afternoons, and to the library to work on projects for the genealogy society on Saturday mornings (when I'm able). My exercise class ended a while back, and I was planning to go to the Santa Clara Senior Center to continue the same exercise regimen, but haven't had the energy. I hope to be able to follow up on that plan before I start chemo again.

I'm still kind of down emotionally, didn't get the excitement I expected from finding out that the cancer is gone, because I've learned from other cancer patients that there is never any guarantee that it's completely, absolutely gone. I'll have regular colonoscopies & CT scans for the rest of my life, and each one will bring back the fear, at least for a while, that it might have come back.

So if you're still praying for me, pray for some emotional relief and a more positive outlook. Thanks.

health update #15 9/24/08

Family & friends -

I'm feeling much better than I was the last time I wrote. It turned out that the thing that was dragging me down was the sleeping pills I've been taking since I started chemotherapy. That's right - it wasn't due to recovery from chemo or radiation or surgery or anesthesia - it was the sleeping pills!

During my first round of chemo I had insomnia so bad that after 4 nights I was starting to feel sick from the lack of sleep. I called the doctor and got a prescription for Ambien. When I talked to the nurse-practitioner I got the full story - both of my chemotherapy drugs have insomnia as a side-effect, and also one of the anti-nausea drugs. No wonder I couldn't sleep.

When I finished the first round of chemo I tried to cut the Ambien down from 10 mg to 5 mg, but couldn't sleep. Next I tried 7 1/2 mg, which involves a pill-cutter, cutting a 10 mg tablet in half, and then cutting one of the halves in half. That worked - I was able to sleep. I didn't decrease the dosage any more at that time - I knew that I would eventually have to wean myself off the Ambien, but it didn't seem worth the effort at that time since I knew that at some point I would be having more chemo.

But then I was talking to a friend who is having insomnia due to chemotherapy, and we discussed the various medications she has tried including Ambien, which she didn't like because it left her with no energy the next day. And I thought "...oh!..." - like a light bulb had gone on! That night I cut the dosage down to 5 mg, which worked fine this time since I had already adjusted to the 7 1/2 mg dosage. And the next day I was awake. Wow!

Three days later I finally started going to the fitness center at the Santa Clara Senior Center, which is something I had been planning to do ever since the exercise class at the YMCA ended, but I hadn't had the energy. They have the same machines as the Y, and trainers on duty all the time, and it's FREE to senior residents of Santa Clara. So far I've been going three times a week, gradually building up to the same routine I had developed at the Y, using the treadmill, then the various machines, then the recumbent bike. I've had a little trouble finding the self-discipline to get myself over there, but it helps to think of it as part of my cancer treatment. I've read several places that there is a high correlation between cancer and obesity, and between cancer and a sedentary lifestyle. And that's me - obese and sedentary. So consistent exercise may be even more important than the extra chemo in preventing another bout with cancer.

And speaking of the extra chemo - it starts tomorrow. I don't expect this round to be as difficult as before, since I won't be having radiation treatments at the same time. According to the doctor the reason why I'm having more chemo is because "6 months total is standard." I've realized from other conversations with him that the design of the treatment is driven by statistics, and having the extra chemo improves the statistical odds.

But to my way of thinking, the real reason why I have to go for another 4 months of chemo is because there is no diagnostic tool that can say definitely that I do not have cancer. At present, the only way to be sure that a particular piece of tissue does not have cancer is to cut it out and put it under a microscope. All of the various scans that detect cancer have a minimum resolution, which means that they can't detect a cancer smaller than a half inch or a quarter inch or some specific size. But it's possible to have a cancer that hasn't gotten that big yet, so the scans can't say that you don't have cancer, just that they didn't detect any cancer. And so I'm going to have 4 more cycles of chemo (16 weeks), just to make sure there isn't any cancer left that's too small to detect. If everything goes as planned, I'll be finished on about January 8.

Right now this is all just very boring. I have reduced my commitments to the various activities that I used to participate in because I don't know how well I'm going to feel; and I can't get a job for the same reason. I've been watching a lot of MASH reruns, and have found some mystery authors that I hadn't read before. But I am SO ready to be done with this!

Thanks for all your support.

health update #16 10/2/08

Family & friends -

I've finished the first 7 days of chemo and now I have 7 days off. As expected, it wasn't too bad. I'm feeling very mildly icky and mildly groggy - but I now know that the groggy feeling is due to Ambien (sleeping pills), which I need during chemo (both of my chemo drugs cause insomnia) and especially the first few days when I'm taking a strong anti-nausea drug which also causes insomnia. But I'm now decreasing the dosage of the Ambien and expect that tomorrow I will be AWAKE!

I didn't have any of the diarrhea that I plagued me during chemo in May & June, so I think that was probably caused by the radiation treatments and not the chemo. Same for the extreme fatigue (aka "mud puddle syndrome"). According to others who have been through it, the second and third cycle of chemo will probably be a little worse, but I don't expect it to get anywhere near as difficult as it was before.

Yesterday I gave myself permission to skip my workout and my cancer support group, because it was the 7th day of chemo. I will probably participate in those Wednesday activities every other week for the duration of the chemo treatments (through the beginning of January, I think). Other than that one miss, I've managed to get myself over to the Santa Clara Senior Center 3 times a week for a workout in their fitness center since I started 3 weeks ago. The hardest part is finding the self-discipline to get myself over there! Once I'm there, I just do what I need to do.

Time for a commercial: did you know that colorectal cancer is the ONLY form of cancer that is completely PREVENTABLE? That's right - not just curable but PREVENTABLE! Mammograms detect cancer; CT scans and PET scans and MRIs detect cancer - after it has started growing and possibly even spread to other organs. But when you have a colonoscopy, they remove all the polyps in your colon BEFORE they turn into cancer. If your doctor gave you a fecal blood test - make sure you get a colonoscopy instead. The blood test only detects problems AFTER they have turned into cancer. And a sigmoidoscopy only looks at a third of the colon - do it right and get a colonoscopy instead! The prep for a colonoscopy is somewhat unpleasant - laxatives and enemas, and getting VERY hungry due to a clear liquid diet - but the colonoscopy itself is done under sedation and is completely painless.

End of commercial.

Except to remind you that if you are related to me, you now officially have a family history of colorectal cancer, which makes the colonoscopy even more important.

Thanks for all your support & encouragement.

Debbie

health update #17 10/29/08

Family & Friends –

The chemotherapy has been much harder than I expected. I thought that since I'm only doing chemo, instead of both chemo and radiation like I had in May & June, that this time it would be much easier - but it hasn't. The doctor thinks it's because of the cumulative effects - the chemo stays in your body for months afterward.

I think that perhaps the reason why this last round has been so difficult is because the infusion machine malfunctioned - the infusion of oxalyplatin last Thursday, which is supposed to take an hour and a half, was done in 20 minutes. For 5 days after I was jittery and restless - new symptoms - and felt much more ill than I did the previous two rounds. The doctor and the nurse-practitioner say it's not related to the speed of the infusion, but I don't agree.

Anyway, feeling so icky for the last 5 days has been the last straw for me. I'm tired of feeling sick, and tired of the insomnia - I now understand the concept of using sleep deprivation as a form of torture. My tremor has gotten so bad it's incapacitating - I thought this was being caused by the compazine (anti-nausea med) but after 4 days with no compazine, there was no improvement in the tremor. I'm tired of being isolated because I'm too weak & tired to go anywhere, tired of having no life, tired of being too weak to even read or watch TV, tired of going farther into debt every month because my only source of income is state disability insurance.

In case you've lost track of all the meds - the 2 chemo drugs both cause nausea & insomnia; one of the anti-nausea drugs also causes insomnia; another of the anti-nausea drugs causes tremor. One of the sleeping pills makes me sick, both of them make me doopey, and we tried a third which had no effect at all, positive or negative. And something, possibly the cumulative effect or possibly the speed of the infusion, has made me shaky, jittery and restless. Yuck!

So I've decided to stop taking chemotherapy.

In reviewing and evaluating this decision, I went back to the reports on the scans I had in March & April. During the colonoscopy, there was a big, ugly tumor, and several biopsy samples were taken which had NO cancer. During the endoscopic ultrasound, 6 biopsy samples were taken and only "some" of them were a problem, and the language that the pathologist used was pretty nebulous. I also had a CT scan which found no evidence of cancer anywhere else. Then after radiation & chemo I had surgery to remove the remains of the tumor, at which time there was NO evidence of any remaining cancer in the tumor.

So the extra 4 months of chemo from Sept to January was not really necessary - just a sort of insurance policy, recommended by my oncologist because 6 months of chemo is the "standard" and because there is no diagnostic tool or scan which can say definitely that there is no cancer - just that they didn't FIND any!

I think that what happened is that I had a great big ugly tumor, with a little bit of cancer in it which was just starting to be active - and they killed it with the first, very aggressive round of chemo & radiation.

Anyway, I made the decision to stop on Sunday, and am just now, on Wednesday, beginning to feel somewhat human again - like I might actually feel like putting on my Raggedy Ann costume on Friday night to answer the door to the neighborhood kids.

I feel good about the decision - about feeling better, about getting my life back, about going back to work (don't know how long it will take to feel well enough for that), about possibly being able to go back to the gym again next week, feeling well enough to go to my support groups and to the library on Saturdays.

I have an appointment next Tuesday with the doctor and he said to keep the appointment because there will be followup stuff, like a CT scan every few months. But I don't think he's going to hassle me about the chemo too much. I get the feeling that he thinks like I do, that this extra chemo is unnecessary, but he couldn't say so because he has to prescribe the "standard".

It's not over - for cancer patients it's never over. I will have regular scans & colonoscopies for the rest of my life. They will gradually become less frequent, but they will never stop and the worry will always be there. But for now, I'm looking forward to getting my life back.

Health update #18 12/9/08

Family & friends –

Shortly before my last update, I had quit chemotherapy because of extreme symptoms due to the malfunction of an infusion pump which delivered in 20 minutes a dose that was supposed to take an hour and a half.

To continue from that point - after about 10 days I started to feel much better, so I went to get a flu shot. That made me feel worse for a week or so. Then I felt better for a couple of days, and then worse again, for no apparent reason. I finally decided that the new symptoms were due to depression, which is very common in cancer patients AFTER they have finished treatment. We hold ourselves together and just put one foot in front of the other until we get through it, and THEN we fall apart.

Some of the symptoms I have are very similar to those I had during chemo, but also similar to the depression I experienced 25 years ago, after Jim & I split up: very sensitive stomach, so that I can only eat very small amounts of bland food; and exhaustion that keeps me lying on the couch most of the time. I also have a lot of dark thoughts, about things like the possibility of the cancer coming back, and other diseases, and the difficulty of finding a job in the current financial crisis and my mounting credit card debt from the amount of time I've been out of work in the last 6 years, plus currently trying to get by on state disability income; plus all the violence in the world - wars, terrorism, murders, cruelty, etc. As I said - very dark thoughts. Most of the time I can keep these thoughts out of my head, but for the past 4 weeks or so, they've been very invasive.

I started taking trazodone, which had been given to me as a sleep aid and which was prescribed as an antidepressant 25 years ago - but it didn't help. Last Wednesday I went to my cancer support group, and they suggested counseling, exercise, and possibly antidepressants. On Friday I talked to one of the nurse practitioners that works with my oncologist. She said the oncology department doesn't have any counselors, even though depression is very common among their patients, and that I need to see my primary care doctor. She also recommended exercise, even if it's just a little, so I've started going for a 5-minute walk twice a day.

I saw primary doctor yesterday, and he said the drug I've been taking is mostly for sleep problems and only has a little antidepressant effect. He prescribed Zoloft, which takes a while to take effect - it may be weeks before I know how much it's going to help. He also strongly recommended counseling or therapy, and he wants me to come back in 3 weeks for a progress report. He's been really great - after he sent me for the screening colonoscopy which started all this, he watched my medical record, and when the diagnosis of cancer showed up he called me. I've been sending him my update emails and he's actually been reading them! And when I saw him yesterday, he had read the notes that the nurse practitioner put in my chart last Friday. He's really been paying attention.

Last week at the support group we had a visit from a counselor who had cancer last year, and who has offered free counseling to anyone in our group - up to 10 sessions. I'm not sure how I feel about her - she's not licensed, and she's into Zen and meditation - but I needed a counselor and don't have any money, and

there she was! And as several people have pointed out, I shouldn't make a decision about her until I've had at least two sessions with her. So I have an appointment with her on Friday afternoon. She's in Palo Alto, which is farther than I want to drive, feeling as crummy as I do, but Ann is going to give me a ride. And if she doesn't work out, my doctor told me to call my insurance and have them recommend someone who is in their network, so at least part of the cost will be paid.

I think a feeling of isolation is contributing to the problem - I just don't have the strength to go anywhere, so I've missed my support group, and Saturday mornings at the genealogy society. But Ann calls every few days, and Beth comes over for a visit every 3 or 4 weeks. Beth took me to Thanksgiving at our step-sister Kathy's house in San Mateo, and I had a good time, even though I spent part of it lying on the couch. Ann took me to the support group last week because I wanted to meet the counselor. And if I decide to see her regularly and Ann isn't available, I still have the group of friends who gave me rides to the radiation treatments in May and June. So I'm being taken care of.

Thank you for your ongoing support and prayers.

Health update #19, Saturday, 3/14/09

Family & friends –

I have good news, bad news, worse news, and an annoyance.

The annoyance is that suddenly last Tuesday my phone line had so much static that I was unable to send and receive email or to access the web. I tried all day, and finally got a good connection at 9:30 pm. Wednesday I wasn't able to connect at all, even at 11 pm. Thursday I finally got a good connection late in the afternoon; and I called the phone company - they are going to send out a repairman on Monday. Friday I was unable to connect. So although I'm writing this on Saturday, I don't know when I'll be able to send it.

The worse news is that it looks like the cancer has come back. I had a CT scan in December that was supposed to give a "baseline" for comparing with future scans. But there was a shadow where the tumor had been. They said it was probably scar tissue, but in order to be sure, they moved up the date for my next scheduled colonoscopy. In the pictures from the colonoscopy, there is an ugly polyp exactly where the tumor had been. And yes, "ugly" is exactly the term all the doctors have used when discussing it - not exactly a medical term, but accurate. It also is very fast-growing, since all the tissue was removed from that area only 6 months ago.

The next week was very difficult, waiting for the results of the biopsy samples that had been taken during the colonoscopy, and not knowing. I find "not knowing" to be one of the hardest things to deal with. If I know what's happening, then I can figure out what to do, and deal with it. But when I don't know what's happening, I can't deal with it and I'm left in limbo - very stressful.

After 6 days of stress, I finally got the call - no cancer! I saw my oncologist and he confirmed it - no cancer! I felt that a huge weight had been lifted from my back. Because the polyp was so fast-growing, and so ugly, and in exactly the same spot as the previous tumor, the doctor wanted it removed as soon as possible, and I agreed. So he said he would talk to the gastroenterologist and the surgeon, to figure what was the best way to remove it. The gastroenterologist was Dr Simpson, the one who did my first colonoscopy - I didn't like the guy who did the most recent one. It was Dr Simpson's office who called me

back and asked me to come in and see the doctor, and I thought "Good! They've decided that they can use the simpler method to remove it." But when I saw Dr Simpson, he had very different news for me - he was sure the polyp was cancerous, even though all the biopsy samples had been negative. And he had convinced all the others at the tumor board meeting, including my oncologist. And they all agreed that I need a colostomy, where they remove the whole rectum and route the end of the colon out through an opening in the abdomen, and attach a bag to it to collect the poop. This is the same surgery that I had fought against last summer, saying "I don't want to carry around a bag of shit for the rest of my life!" So I was shocked, to say the least. I felt like I had been hit by a truck. I was in despair. The doctor said I should have an endoscopic ultrasound and another CT scan as soon as possible, and that I should make an appointment with the surgeon for a few days later, after the results had come in. I agreed and went home, still in despair.

I called the ostomy nurse at El Camino Hospital, which several people had told me to do. She helped me a lot - she was very calm and matter-of-fact, and made it all seem manageable. She told me about the different kinds of bags and so forth, and that sometimes people do have problems with an ostomy, but that the problems are all solveable. She also told me about a once-a-month ostomy support group. At the end of our conversation I felt somewhat better.

Then I talked to the therapist who I've been seeing for depression. She used the word "grief", and that helped. Despair is a bottomless pit that goes on forever, but grief is a process that I understand and can work through. And I realized that she was right - I was grieving for the body part that I was going to lose, but also grieving for the loss of normalcy. I felt that this loss was going to make me different from everyone else and an object of pity. Identifying all this as grief instead of despair made it seem more manageable.

And then I went to the ostomy support group, last Tuesday night. I went looking for information, of course, but also to be with a group of people who all have ostomies, to help dispel the feeling that I would not be "normal". And I got exactly what I needed. There were about 20 people, most with ostomies but also a few caregivers. They had a short program about their new website, but then spent most of the time focussed on 2 people who were having problems with their ostomies. They asked lots of detailed questions and made a number of suggestions, but also kept saying "you need to go see the ostomy nurse. Not the doctor - doctors don't know anything!"

Then they wanted to know my story, so I told them - all the details, and the reasons why the doctors were sure it was cancer, even though the biopsy samples were all negative. They were very emphatic that I should not have such a life-changing surgery until the doctors could prove that it was cancer. Everyone said this, over and over. (And it was exactly what I needed to hear: I had doubts about having the ostomy surgery without proof of cancer, but didn't want to seem too argumentative, after refusing their recommendations on the first surgery and then having the cancer possibly come back. But the group gave me courage.) First they wanted me to get a second opinion, from someone outside the Camino Medical Group. I said a second opinion based on the facts I have now would be just another opinion. So we continued to discuss it, and finally ended up with a plan - I would tell Dr Simpson that I need proof of cancer before having the surgery. If he agreed to take more samples, then I would stick with my current doctors. But if he refused, then I would find a doctor outside the group. They even told me how to do this - ask the ostomy nurses for recommendations.

So for the next few days I played telephone tag with Dr Simpson. He called with the CT scan results on Tuesday night while I was at the ostomy support group; I called his office Wed morning and left a message. He called Wed night while I was at my cancer support group; I called Thur morning and left a message. He finally reached me Thur night and told me that the CT scan was basically clean - there were

a few very small spots on the lung, but they were smaller than the resolution of the scan and so not to be taken seriously. We will just watch them on future scans. Then I told him what the ostomy group had said about needing proof. He was sort of taken aback and resistant, but as we discussed it he warmed up to the idea. He said he would talk it over with the other doctors. He called again on Friday night with a suggestion - to have the surgeon remove the polyp with the pathologist standing by, and if he finds cancer then they would go ahead and do the ostomy. I said that sounded pretty scary - to go under the anesthetic not knowing what I was going to find when I wake up. I proposed a variation - to have the surgeon remove the polyp, have the pathologist prepare and examine it in the normal way, which takes a few days, and then if he finds cancer I will go back for the ostomy surgery. So Dr Simpson is going to take both ideas to the tumor board next Friday, and if they can come to an agreement, I am going to follow their recommendation.

And I am once again in limbo, waiting for information and not knowing what's going to happen. But in the meanwhile I feel very well cared for by so many people - the ostomy nurse, the therapist, Dr Simpson, all the people at the support group, the people who have been giving me rides, and the few people who I have told about this so far, all of whom have been tremendously supportive. I feel very lucky. And after so much stress about the ostomy, I finally feel at peace about the path that I'm on - about having the ostomy if the cancer has come back, and about letting the doctors choose the method.

The bad news is finances, which are a problem for everyone right now. My state disability insurance ends at the end of this month, so I need to apply for long term disability from social security. The application is online, which I can't get to because of my telephone line problems! Also, I think the amount is going to be less than the SDI. I was hoping to be back to work by now, but it looks like it's going to be a few more months, at least.

At last! We've finally gotten to the good news! My depression is getting much better. The first antidepressant didn't do anything for me, so my doctor switched me to another one, in a very small dose. A month later he increased the dose and the side-effects showed up - constant dizziness, all-over shaking, headache, queasy stomach. But after a few weeks the side effects have pretty much faded and I have more energy. I'm getting done the things that I need to do - and then I run out of energy and lie down on the couch again. But that's okay, because I feel so much better than I did.

That's all for now.

Health update # 19A 3/28/09

Family and friends –

This will be brief. The GI doctor agreed to take his plan (to do both surgeries at the same time) and my plan (to remove the polyp, have it prepared in the normal way, and if the pathologist finds cancer, then have the ostomy surgery) to the tumor board and have them decide. The tumor board decided on my plan, and the first surgery will be this Wednesday, April fools day!

It's a minor surgery with a not-too-long recovery, because there will be no incisions in my skin - he will go in through the anus and scoop the tumor out, like he did before.

And I'm still having problems getting connected to the internet. I'm writing this on one of the library computers. At home I've now tried 2 different computers - my desktop and a borrowed laptop - on 2

different phone numbers on 2 different sets of wires, and all combinations have the same problem. So I'll call my ISP again on Monday.

I'm feeling pretty good, still get really tired in the middle of the day, and I get a fizzy feeling in my stomach when I think about the second surgery - but I'm all right. And I feel very well cared for.

Thank you for all of your encouragement, prayers, and support.

Health update #19B 4/2/09

Hello all you wonderful people –

The surgery went okay and I'm at home, after spending one night at the hospital. The doctor said he expects to receive the pathology report on Monday. More news then.

My internet connection has suddenly started working again. I think probably the phone company (AT&T) got enough complaints that they finally fixed the problem - the same problem that they denied exists in the first place.

Thanks for your thoughts and prayers.

Health update #19C 4/6/09

Family & friends –

The doctor called this afternoon with the pathology results. There was cancer in the polyp that was removed. So I am going to have the ostomy surgery, and probably some more chemotherapy.

The surgery is scheduled for 9 days from now, on Wed morning, 4/15. I will be in the hospital for 5-7 days, depending on how long it takes my new plumbing arrangement to start working properly. I don't know when I will be ready for visitors, but I imagine that by the 3rd or 4th day I'll be pretty bored. I'm still figuring out how I'm going to keep in touch with everyone.

I really am at peace with my decision to go through with the surgery. If you believe in prayer, pray that my peace of mind continues.

And also pray that Obama gets the health care system fixed very soon. My biggest expense every month is for health insurance. And my CalCobra coverage will end 4 months before I'm eligible for Medicare.

As always, I feel very well cared for. I always have rides when I need them, and any other help that I need. Beth was at the hospital last Wednesday when I woke up, and Mary from the cancer support group. And I'm going to get a lot of help from the ostomy support group in the months to come.

Health update #19D - 4/10/09

My oncologist's nurse called earlier in the week and said he has to see me this week, it can't wait until next week, and it's about the CT scan I had 5 weeks ago. So I just got home from my appointment with him.

I figured that the issue was about some very small spots on my lungs, which both the GI doctor and the surgeon had seen, and neither was concerned. I was right - the oncologist wants me to have a PET scan to get more info about the spots, and he wants to do it before I have the ostomy surgery. I could wish that he had developed this sense of urgency 4 weeks ago instead of waiting until just days before the surgery. Oh well.

So I'm feeling a liittle worried about the spots, but also relieved by the postponement. I think part of the anxiety I've been feeling has been from the pressure of all the things I'm trying to get done before the surgery so that I don't have to deal with them during recovery.

I probably won't write to everyone again until I get the results from the PET scan and know what's happening next - probably next week, or possibly the week after.

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Health update #19E - 4/16/09

Family & friends –

My PET scan has been scheduled for Monday, 4/20 at 10 am. I don't know exactly how long it will take to get the results - probably a few days. As soon as I hear, I will send out another email. If I have the ostomy surgery, it will be on Wednesday, 4/29.

All this uncertainty has caused my anxiety level to go up a little and my peace-of-mind level to go down. If you believe in prayer, please pray for peace of mind for me.

Thanks

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Health update # 19F – 4/22/09

Hello all you wonderful people!

I just got the results of the PET scan, and it's completely clean, completely negative, no evidence at all of metastasis. Yay!

So the ostomy surgery is on for next Wednesday, 4/29, early in the morning. Ann is going to take me to the hospital, and there will be at least 2 people there, possibly 3, when I wake up. So I'm well taken care of.

I don't expect to feel real perky when I wake up - this is major abdominal surgery, with 3 serious incisions plus 3 small ones. I have no idea how long it will be before I'm ready for company. Beth will send a status report, possibly Wed afternoon or evening, possibly Thur morning; and another one later in the week when I'm ready for visitors.

Please continue to pray for my peace of mind - sometimes the anxiety creeps back in again. And on Wednesday, maybe you could pray for steadiness for the surgeon's hands?

Thank you for your ongoing support.

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Health update #19G – 4/22/09

I spoke too soon! While I was writing emails and making phone calls about the news this afternoon, the surgery was rescheduled - again!!

It's now scheduled for Monday morning instead of Wednesday, same time - 7:30 am. It's expected to take 3 hours. I will be at El Camino Hospital on Grant Road in Mountain View.

I don't know how many more times it will be changed. :^))) <- a grin with 2 chins

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Health update #19H – 4/26/09

Family & friends -

Looks like this is it - it's Sunday, and nobody has called to change the date again, so the colostomy surgery is tomorrow morning.

I will be at El Camino Hospital for most of a week; maybe even a little longer. They want me to be fully ambulatory and with my re-arranged plumbing working well before they send me home. The hospital is on Grant Road in Mountain View. Visitors are allowed from noon to 8 pm. Beth will send a status report Monday or Tuesday, and another a couple of days later, and she will let you know when I'm ready for visitors.

I won't be able to drive for several months after the surgery so I will be calling on my helpers to drive me to errands and stuff for quite a while.

I'm not worried about the surgery. Most of the anxiety I've been feeling is about my list of things that have to be done before the surgery. I think it's going to be a relief when they knock me out and I can quit thinking about that list!

Pray for steadiness for the surgeon's hands.

Thank you for all your support and encouragement.

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From Beth –

4/27 Dear All,

Debbie came out of the surgery ok. When I left Mountain View, she was still sleeping, but had opened her eyes a few times and engaged with me. She asked that I send out an email to everyone, so here it is!

I am exhausted after 7 hours at the hospital. More when I know more.

Sincerely,

Beth

Health update emails

5/2 Dear All,

I visited Debbie today and she is feeling better. She asked that I let people know that she can have visitors and phone calls. She is at El Camino Hospital, at 2500 Grant Rd., Mountain View 94040, rm 531B. You can call her at the hospital, 650 940 7000. Ask for room 531B.

Hope all is well.

5/4 Dear All,

Debbie is recovering nicely; walking around the 5th floor 3 or 4 times a day, eating mostly normally. She needs help getting herself and her car home sometime on Wednesday. If anyone can possibly help, give her a call at El Camino hospital at 650 940 7000 and ask for room 531B.

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From Leanne

Dear Friends of Debbie,

This morning Debbie was surprisingly discharged from the hospital. I had called an hour after she was told and offered to pick her up. I was concerned, since she sounded very weak on the phone, that they would let her go home so soon. We discussed our concerns with her case manager and it seems the bottom line is that she feels Debbie would be risking less danger from infections at home and also get more rest there. Tomorrow a home health care person will visit but how many more times is not known.

Right now Debbie is fuzzy headed from medication and very tired. She's sleeping and would appreciate no phone calls tonight. (I checked her freezer and she has some TV dinners and isn't on a particularly restricted diet except for fiber). She said that she will E-mail all of us as soon as she is able regarding phone calls and visits and rides.

Please join me in keeping Debbie's healing and stamina in our thoughts and prayers. I've witnessed what an impact it is on her to feel everyone's care and concern. It is definitely what is making a really tough situation manageable.

Leanne Wiese

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Health update #20 – 6/5/09

Family & friends –

I'm going to include a few medical details, so if you're queasy you may want to skip certain paragraphs, or have someone else edit it for you.

Sorry it's taken me so long to send this. I'm still very weak from the surgery, and have been doing only the minimum necessary to keep myself fed & relatively clean. And it's still painful if I try to sit for very long at a time. It's taken me 4 days to write this, a few paragraphs at a time.

The ostomy surgery took longer than expected because of adhesions between the rectum and everything else around it, caused by the radiation treatments a year ago. But other than that, things went smoothly. I was in the hospital 8 days; wasn't really ready to take care of myself when I went home. But I got by with the help of wonderful friends and a home care nurse. Turns out the hospital sends people home as soon as

they can because they're under mandate from the state licensing authority to reduce their incidence of multi-resistant superbugs. They don't say that to the patients, of course; the closest the Discharge Coordinator would come is to say I would be safer at home.

I used to think of El Camino Hospital as being of very high quality, but no longer - due to the superbugs, and to a couple of incidents that happened while I was in the hospital. I'll tell you about one of them: my ostomy bag had leaked, which means there was poop all over my abdomen, my gown, the bed - a mess. I pushed the call button and a nursing assistant came in, then she called the nurse. The nurse removed the bag and my gown, then the assistant went to take care of another patient. Then the nurse got paged because one of her patients was bleeding, and she left. So there I was, naked except for a thick layer of poop. I couldn't get to the bathroom to take care of it myself, because if I got up some of the poop would fall off and make more of a mess, and because between my bed and the bathroom was the door between the room and the hallway, which has a BIG window with no way to cover it - no shades, curtain, blinds - nothing (stupid). So I lay there until I pressed the call button again, and someone else came in and took care of me. The charge nurse came in later and was very apologetic, and the nurse who left me in that state also apologized - but I'm no longer impressed with El Camino Hospital. It seemed to me that the nurses were always in a rush, so I asked several of them if they were short-staffed, and all of them denied it - but I think maybe that's just another thing they are not allowed to say to the patients.

On Monday of the second week, my doctor said I would go home on Wednesday. So Beth sent out an email with that info, also letting my helpers know I would need a ride on Wed. Then on Tuesday morning, the doctor comes in and says I'm going home today. Eek! Panic! While I was in the hospital the only things I had to do was go for a little walk 3 or 4 times a day, and sit up to eat meals - other people took care of everything else. After each activity I took a nap. I didn't even have to get up to go to the bathroom because of the catheter. And then suddenly the catheter is out, I need to empty the ostomy bag for myself, empty the drains from the two major incisions, clean myself up and get dressed, pack my things up, and call people to find a ride. And with no time in between for naps! I got some of it done, but then was exhausted and just couldn't do any more. At that point Leanne called up and asked if I needed any help! (I think maybe she & I have some sort of psychic connection.) So Leanne came to pick me up, and she packed my stuff while I dressed. She also went to battle with the discharge coordinator, insisting that I wasn't ready to go home - it was great! It made me feel really good to have someone advocating for me. This was when the discharge lady said I would be safer at home, and even though she never mentioned superbugs or infection, I knew what she meant - so we left.

Several people came to visit while I was getting ready to leave, and it was really nice to see them. I apologize to anyone who came after I left, thinking I would be there another day which was what the doctor had told me! But he changed the plan in mid-stream, and there wasn't much I could do about it.

At home I was very weak, with not even enough energy to read or watch TV, and with almost no appetite. But Leanne brought me some food and made me eat some of it; and Leanne, Mary, & Beth helped out by taking me to doctor visits or the store, or going to the store for me; and Leanne even provided me with a shower stool so I could take showers sitting down - I can't stand up long enough. Bob C helped by writing checks for me when I needed to pay my bills - all I had to do was sign. And I had a home care nurse 3 times a week until this week - she changed all the dressings after I took a shower, and checked all the incisions and my vital signs. And Ryan flew out from Colorado last Friday and spent all of Saturday and most of Sunday cleaning house for me - Wow! what a difference!

My progress has been very slow - some improvement in appetite, a little improvement in stamina, but I'm pacing myself very carefully, because it doesn't take much activity to exhaust me again. I'm not driving

yet, mainly because it hurts to sit. I'm watching some TV, lying on the sofa. I've been over to Leanne's a couple of times to take naps in her garden.

I've been back to the surgeon 3 times - once to have the sutures & drains removed, twice due to symptoms that I thought might be problems. He's been very patient & said that this very slow recovery is to be expected after such a major assault on my body.

My main focus has been learning to manage my ostomy and the pouch. I've had some problems with that, mainly leakage and very red, irritated skin around the stoma. I'm trying out samples from different ostomy supply companies and talking to their consultants to figure out solutions.

I would enjoy phone calls, and even short visits if people don't mind me lying on the couch while we talk (:^))) (the last 3 parentheses are a grin and a double chin)

Thanks again for all your prayers, good wishes, help, and support.

health update #21 - 7/1/09

It's been almost a month since my last update; and while I've had things that I wanted to tell you, most of them have been subject to change from each day to the next. So each day I wait until the next, and then of course there are more things that are likely to change. So then I wait another day...

And now it's time to quit procrastinating.

I saw my oncologist in the middle of June, and he said he wanted me to start chemo again as soon as possible. I said I was still too weak from surgery. He said at this point (6 weeks) I should start improving faster. I said we'll see. So we made an appointment for 2 weeks later (last Thurs). He also said that since I still have neuropathy from the oxaliplatin he was going to replace that with irinotecan (given by IV at the infusion center every 3 weeks), and the second drug would still be xeloda (pills, so I can take them at home). [This is Plan B]

When I saw him again I felt significantly better (he was right!) My tailbone only hurts a little so I can sit for longer and I'm off pain pills; I've been driving short distances; taking 2 short walks a day; eating much better; and managing the ostomy is gradually becoming easier and more routine. So I had my first chemo treatment of this round on Friday 6/26, but the doctor had changed the second drug from xeloda to erbitux which is an infusion given every week. [Plan C] On Friday, the total time for the 2 infusions plus pre-meds was about 4 1/2 hrs. That's okay, I didn't have anything better to do. When I got up to go home I was very weak & shaky. That got worse for the next few days and then started improving a little. So I've spent most of my time for the past 5 days sleeping, in bed or on the couch. I've had a few visitors, and my friends are taking good care of me.

The next surprise was on Saturday when I received a letter from the insurance company stating that they had denied approval for the irinotecan-erbitux combo. Which means that the doctor had gone ahead with the treatment without the pre-authorization. I didn't let myself worry about it - it's his bad, not mine, and I'm not going to pay for it. Besides, it was Saturday, so there was no action I could take.

On Monday I lay siege! I had decided on 2 calls each day, one in the morning and one in the afternoon. The first day I left a message for the lady in the oncology dept who takes care of approvals, and a message

for the doctor. The second morning I left a message for the doctor's nurse, and sent an email to the doctor. That afternoon I received a call from the nurse and an email from the doctor, both confirming that they were working on it. So I wasn't worried any more. I knew that the doctor really wants me in chemo as soon as possible so he's motivated to straighten it out; and that I am not going to have any more treatments until I see the approval in writing. So I have a little leverage - I've learned that finding the right lever makes a wonderful difference!

The doctor called me this afternoon; the insurance co. finally approved irinotecan, but won't approve erbitux unless several other regimens have been tried first. So here's Plan D: irinotecan on a 2-week cycle (an infusion every other week) and xeloda also on a 2-week cycle (pills daily for a week, then a week off.) We won't start this Friday, because I just had a 3-week dose of irinotecan last Friday. So I think my next chemo cycle will start around July 16 or 17 (but maybe it will be Plan E?). Between now and then I might feel gradually better, or I might not because irinotecan can cause diarrhea that commonly strikes around the middle of the second week. I expect this round to be easier overall than it was a year ago, because this time I'm not having radiation at the same time.

Another common side effect of irinotecan is hair loss, so the next time you see me, I might be wearing a red wig!

Health update # 22

Hello all you wonderful people!

I'm back to plan B: irinotecan & xeloda on a 3-week cycle. The last treatment, 7/16, was on a 2-week cycle, and there wasn't enough time to recover from the previous dose before the next one, 7/30. The last few days I had enough energy to do one thing each day, but that one thing, like grocery shopping, wore me out. So I got the grocery shopping done, and the bills paid, and got to the clinic to have blood drawn. But I didn't get a shower, or take out the trash & recycling, or write this update, or put all the groceries away, etc. My doctor agreed to change me back to the 3-week cycle so I'll have a little time to feel normal and get things done before the next treatment.

During the last cycle, I felt weak & shaky after the infusion but okay on the second day - so good that I babysat with my grandkids for 3 hours. (Amy was here with the kids for about 10 days and I got to see them 3 times - it was wonderful!) But that night & the next day I slept 20 hours - from the chemo, not the kids.

This time I also felt weak & shaky yesterday, but pretty good today, so I put away some more groceries, took a shower, and got started on this update. If the pattern continues, I'll sleep 20 hours tonight & tomorrow and then a little less each day after that.

The acne that was caused by Erbitux continues to fade. But it was really awful, and I'm grateful to the insurance company for not approving the drug.

The irinotecan causes hair loss for a lot of people, and mine is definitely falling out. I'm really thankful to my cancer support group, many of whom have experienced hair loss, for enabling me to feel comfortable with this, and to look on it as a chance to play with wigs & hats. I found the curly red wig I wanted - it's called "Lucy". Next thing is to see if I manage to find the nerve to buy it, and then to actually WEAR the thing!

I've bought 4 hats so far - one in a store and then ordered 3 more online. Three of them are turbans, VERY soft, stretchy and comfy; and one is a denim hat like a cloche with a very narrow brim and little flowers embroidered all over. This is fun! But dealing with all the falling-out hair is becoming annoying; I think I'm going to shave it off pretty soon.

So here's my life for the next few months (I don't know exactly how long): a week or so of sleeping most of the time, a week or so of slow improvement, and a week or so of feeling somewhat human and getting done all the things needed to get me through the next few weeks. When I feel able I'll go to the cancer support group, the ostomy support group, game night, and genealogy society meetings; and I'll go to lunch on Saturdays with the work group from the genealogy society. And when I don't feel able - I won't.

Thank you for all of your help, support, prayers and good wishes.

Health update #23 – 10/18/09

Family & friends -

You haven't heard from me for a while, because there hasn't been anything new to say. I'm still having chemo in 3-week cycles, feeling kind of poorly & sleeping all the time for the first week, getting up & around a little the second week, and then feeling a little better the third week which is when I have to do all the things like grocery shopping to prepare for the next cycle.

With each cycle I generally feel a little worse than the last cycle, except that with this current cycle I've been feeling a little better than last time. So much for trying to see a pattern.

I haven't been nearly as isolated as I was during the recovery from ostomy surgery. I've been going out to lunch with friends on Saturdays, 2 weeks out of every 3. Also going to cancer support group on 2 wednesdays out of 3. Also going to the ostomy support group and games night, each once a month. So every time I get lonely, there is some activity coming up.

So that's the same-ole-same-ole news. The GOOD news is that this Thursday will be my last treatment. Yay!

Four weeks after this treatment, I'll have a CT scan to determine the results of the treatment. And then the scary part - waiting for the results of the scan. If it comes up clear, then I go back to the surgeon for minor surgery to fix a few problems with my stoma. He says it will be out-patient surgery, which means I'll go home the same day. We'll see.

I'm looking forward to joining with family for Thanksgiving and Christmas this year, which I wasn't able to do very well last year.

And then, I hope to be able to get on with my life!

Ryan & Amy have finally realized their dream and gone overseas. Ryan is enrolled in a doctoral program in his area of history. For the most part, things have been going pretty smoothly for them.

Thanks for all your caring & prayers.

Health update #24
12/3/09

Family & friends –

I keep thinking I'll write another update as soon as I have something definite to say. But I'm finding out that with cancer, the bad news is definite but the good news is always much more tenuous. They don't say "you don't have cancer" but rather "we don't see anything on the scan that is definitely cancer, but this area right here is sort of nebulous, so we're going to schedule another test", or a biopsy, or we want another scan in a few months, or something of that sort.

That's my situation right now. I had my final chemo treatment on Oct 22, then a CT scan on Nov 20, the Friday before Thanksgiving. They usually wait 3 months to do the CT scan, but when the cancer recurred last spring, it came back very quickly and grew very fast, so by the time I had the CT scan, the tumor was already 2 inches long. So this time we didn't want to wait so long.

When my oncologist, Dr Tai, called me with the results the next Tuesday, he said there was one area of concern, a "thickening" of the tissue where the tumor had been. It's very nebulous and they can't tell what it is - maybe scar tissue, or inflammation, or cancer. He said that we would probably do another kind of test or possibly a biopsy, but that he would discuss it with my surgeon before I came in for an office visit.

When I saw him on Tuesday, Dec 1, he and Dr Legha (the surgeon) still hadn't figured out what the "thickening" was and they had decided to just watch it closely. He questioned me very thoroughly about possible symptoms of a recurrence, wants to see me again in a month, and I'm to have another CT scan in 2 months, to see if it has gotten larger (cancer), or stayed the same (scar tissue), or gotten smaller (inflammation).

I'm comforted to have at least 2 doctors looking at the data, like I get a second opinion without even asking for it. I'm also comforted by the fact that Dr Tai is keeping a close eye on me, and also that he didn't seem worried about it at all - he was very cheerful during my visit. He took us (me and my friend Mary) into his office where he has a very large monitor for viewing scans. He showed us the whole CT scan, from top to bottom, explaining the details of what we were looking at - bones, heart, lung, liver, etc., which all had clear outlines on the scan. When we got to the bottom of the tailbone, he showed us the area of concern - which was a vague, fuzzy, irregular thing, right where the tumors had been.

I was prepared for a less-than-definitive diagnosis, because my friend Ann, who has been doing this for a couple of years longer than me, says that every time she has a CT scan they find something vague and she has to have another test, and it always turns out to be nothing.

This all just confirms a conclusion I reached some time ago, that although the drug companies keep coming up with better and better treatments, the diagnostic tools are still pretty weak. I guess there isn't as much profit in improving the diagnostic tools.

In the meanwhile, I'm not recovering from chemo as fast as I had expected. It's now 6 weeks since my last treatment and I still haven't regained my stamina. I can stay up for about 2 hours (longer if I really push myself) but then I go back to sleep. I've been sleeping about 12 hours out of every 24. This was the only thing that had Dr Tai concerned during our visit. He did say that occasionally a patient gets really knocked out by all the treatment and takes longer to recover, and that I have certainly had more treatment than most. So we'll just wait and see.

I've been able to keep up with all the activities that I reported in the last update, some weekly (cancer support group and Saturday lunch), some monthly (ostomy support group and Trivial Pursuit). And it looks like I'm going to be involved in the landscape committee for my homeowners' association.

And I have a new hair-do - or maybe it's a hair-don't! About 2 1/2 weeks after my last chemo treatment all the rest of my hair came out over a period of 3 days, all except a little tuft in the front which leaves me with bangs peeking out from under my hat. I wear a hat most of the time, usually something soft and stretchy like a ski cap. About half of the ladies in my cancer support group have experienced hair loss, and they all say their hair started to grow again 3 months after their last treatment - so I know about what to expect. If I start job-hunting in January I think I'll get a wig. I feel lucky that I'm going through this part of it in the winter. I can't imagine how awful it would be to wear a hat or wig in the summer!

On top of old baldy,
without any hair,
I took off my ski cap,
gave everyone a scare.

Ryan and Amy and the kids have been in Azerbaijan for a couple of months now. Some of our concerns have resolved themselves easily - like a part-time job for Ryan, and access to books in English for his doctoral research. But just living in such a different culture still presents challenges; for example, the post office doesn't deliver the mail, even though they are in the capital city - they have to go pick it up. Thanks again for all your prayers and good thoughts. Unless something interesting happens, I probably won't write again until after the next CT scan at the end of January.

Health update #25
12/21/09

Family & friends –

On Wednesday I had the surgery to correct some problems with my stoma. It was outpatient surgery, not too bad. I was home in the evening and feel okay, except I still have no stamina and am sleeping 12-14 hours each day.

I'm not happy with the results. There were 4 problems that I needed fixed. Two of them were improved or fixed, two were made worse, and 2 new problems were created. I won't give more info except for those who let me know that they want all the poop details.

I saw my surgeon for a followup visit this afternoon. He said that he was not able to access everything through the stoma and if I need the rest of it fixed, I will need abdominal surgery - which means another hospital stay and 6 more weeks of recovery. (He had also told me this in the hospital on Wednesday afternoon.) I'll have the surgery after the first of the year.

I'll be spending Christmas in Sonora with Constance. It looks like all 5 of us will be together this year, which doesn't happen very often, so I'm looking forward to it.

Happy holidays

Health update #26
1/30/10

Hello all you wonderful people!

In the last update I told you about the outpatient surgery which was supposed to fix the problems with my stoma but instead made things worse. I didn't discuss the details with the surgeon because I was so angry that I thought I would blow up. I told my oncologist about it and asked him for a referral to a colorectal specialist (which my surgeon is not). He said I had to go back to the surgeon and talk with him about the details, and ask *him* for a referral to another surgeon.

So I did. He was not very responsive, either made excuses or denied the existence of the problems ("it wasn't like that when I closed you up"). This confirmed my growing lack of confidence in him - which feels to me like a loss to be grieved, because I really like him and I had trusted him so much. He said he would put through a referral to Stanford, because CMG no longer has a colorectal surgeon. (She left and went to Stanford.)

In the meanwhile, I asked around at my ostomy support group for recommendations. I got a short list of doctor names, and two people recommended the same doctor at Stanford. (One person recommended a certain doctor, but 4 (four!) other people said NOT to go to that doctor! Interesting). I never heard from Stanford, finally made a bunch of phone calls and found out that the "managed care" group at my medical group had decided not to send the referral because my insurance didn't require it! I decided to leave it alone because I had noticed that some of the problems seemed to be healing themselves. So I will just watch until it stabilizes and then decide whether I want to talk to another surgeon.

In the previous update (sent Dec 3) I talked about a CT scan which showed a nebulous something which the doctor said we would just watch to see what it does. I had another CT scan last week, which showed that the "something" had shrunk about an inch in each direction - which means it is probably just inflammation. Yay!

I had a great Christmas. Clark drove me over to Constance's house in the Sierra foothills (gold country!). Even Roger was there - it was the first time in quite a while that all 5 of us have been together. Constance's son Jody has a 16-month old son named Gage. Gage was a little leary of me at first, but once he realized that I would go outside and take walks with him, he decided I was all right. I absolutely LOVE following toddlers around in the little random walks they take. We went back inside the house for a while, and then he came over and started tugging on my jacket, which was on the back of my chair. I gave it to him and he got really mad at me. His mother took pity and explained that when he wants to go for a walk, he brings her jacket and her shoes, so tugging on my jacket meant I was supposed to put it on and take him for a walk. Pretty smart kid. I think we took 4 walks in all and I had a ball, just following him around and keeping him out of trouble.

I had a cold right after Christmas; I assume I got it from Gage (but it was worth it!). After I thought the cold was gone, I started coughing, which has lasted about 10 days. My hardest problem is finding a medicine that will suppress the cough long enough for me to get some sleep. I've quite a few rough nights in the last 10 days, because my "6-hour" cough medicine usually lasts 2-3 hours, if that. I brought a couple of other things home today and hope they will work better.

After I get rid of the cough and start sleeping again, I have to work more on building up my stamina. I've gotten a little more involved in the landscape committee for my homeowners association, which involves some walking around, so that helps.

I feel like I'm slowly starting to get some of my life back. Next thing after building up my stamina is to look for a job (unless of course I win the publishers clearinghouse \$10-million prize).

Love
Debbie

Health update #27 May 11, 2010

Family & friends –

I knew that it's been a while since I sent an update, but I didn't realize that it's been more than 3 months! Sorry about that. I kept waiting until I have some good news to share - and until now that hasn't happened. But at last I have good news.

The most important news is that I've been clean of cancer for a full year! That's a major milestone - the number of recurrences drops off steeply after the first year. I didn't realize that it had been a year because I was counting from the end of chemotherapy, which was in October 2009. But the oncologist says they count from when the cancer was removed - my ostomy surgery which was in April 2009. So that was a wonderful surprise, kind of like a birthday present. Come to think of it, it is kind of a birthday. Maybe I'll celebrate my birthday on April 27 from now on.

I will continue to have regular visits with my oncologist, with blood tests before each visit. He said there won't be so many CT scans, that now he's mainly watching the blood tests for liver problems, because if the cancer does return it would most likely be in my liver. He also asks me for lots of details about how I'm feeling because if there is a recurrence, it would first show up in symptoms like loss of appetite, etc.

The other good news is about my stoma. After my last update I dithered for a few months - I was more & more convinced that the surgeon who created my stoma didn't know what he was doing, but not sure that fixing the remaining problems was worth another major abdominal surgery and the subsequent months of recovery. I finally decided that if I'm going to do it, I have to do it now rather than wait, so I went to see the doctor at Stanford who had been recommended to me. He said he could fix the problems by working through the stoma instead of having to make a large incision, so I said - let's do it!

I had the surgery in March, only stayed at the hospital overnight. The doctor said he removed about 6 inches of extra intestine which, combined with the fact that the other surgeon had made the abdominal opening way too large, accounted for the prolapses. He said he fixed a small hernia, also caused by the too-large opening. The stoma was a little flatter than I'd hoped, and the skin on the right side of it still dipped way down, but overall it was much improved.

Ten days later the stitches pulled out of the skin on the right-hand side of the stoma. The ER doctor at Stanford said I could leave it open until my 2-week follow-up with the surgeon 5 days later, or he could stitch it up - but he wasn't sure the stitches would hold. I told him to stitch it up, rather than leave me with an open wound. Five days later, on the day when I went back to see the surgeon, the stitches pulled out again. The surgeon said we would have to leave it open because the too-large opening was causing too

much tension on the stitches in my skin. He said it would heal from the bottom up and pull itself together and leave me with skin, not scar tissue. I was skeptical. A stoma nurse show me how to pack it, with a microbial gel at the bottom, then fill in up with healing powder, then cover it with a piece of sticky elastic stuff and apply the pouch barrier on top of that. She also showed me various methods for dealing with the low area on the right, to minimize leakage.

So for the next 6 weeks I cleaned it out and re-packed it every other day. At my 4-week visit with the surgeon, he was surprised at how fast it was healing. At the 6-week visit the skin had closed completely, and the surgeon said we were finished and there was no need for me to come in again unless I have problems. The stoma now sticks out a little more than a half-inch - just right. The low area seems to be filling in, and one of the methods the nurse showed me for dealing with it is working, and I have no more leakage. Finally, after a year of frustration, I have a stoma that's working properly.

I feel like I'm starting to get my life back! I'm taking a longish walk each day to build up my stamina, and will start looking for a job soon. I'm now chair of the landscape committee at my homeowners association, a volunteer job that can take as much or as little time as I'm willing to give to it - but it's very satisfying. And last weekend I taught 2 of the classes for the genealogy society's twice-yearly beginners seminar, which I wasn't able to do last fall or last spring.

Ryan & Amy and the kids are still in Azerbaijan and they called me for Mother's Day. Ryan is working on his doctorate in International Relations, currently taking 4 independent study classes, each with a long term paper. The cost of living there is higher than they were told, and not all of their support has come through, so they're not sure if they will be able to stay as long as they planned.

I think my regular health updates have come to an end. I will probably tell you when I get a job, and will report any further health issues - but I don't expect any. I want to thank all of you for your help and support, your prayers and good thoughts. Knowing there are so many people who care about me has made a huge difference for me in the turmoil of the past 2 years.

THANK YOU

One year later:

The too-large-opening mentioned in my last update turned out to include the abdominal wall, and I developed a hernia about the size of a 4-month pregnancy (except I was only pregnant on the left side!) I had major surgery to correct this in April 2011. Recovery was very slow; it took about three months to even start to get my stamina back.

During the intervening year I continued to have problems with leakage under the barrier, which caused red, raw skin for about an inch around the stoma in all directions. After the hernia operation my stoma had changed size & shape again so I called the pouch manufacturers for another set of samples - and finally found something that works! If anyone is reading this who has a stoma and leakage problems, the secret is that most "convex" barriers are not actually convex - they have a little bit of slope but are flat at the bottom. The pre-sized (NOT cut-to-fit) convex barriers by Coloplast and Hollister are actually convex all the way to the bottom and put enough pressure on the skin around the stoma that I no longer have ANY problems with leakage. It only took me two years to figure this out, and I had to figure it out on my own, despite many ostomy support group meetings, conversations with multiple ostomy nurses,

conversations with multiple manufacturer's reps, and postings on the UOAA message board. Why didn't someone tell me this sooner?

I am now president of my homeowners association (477 units), and still teaching for the genealogy society.

And when my hair grew back in, it came in curly on top, which is common for people who lose their hair during chemo. And more than a year later it is STILL curly, which is NOT common. Looks like it's going to stay that way.

In the meanwhile, Ryan & Amy have returned from Azerbaijan and are living in Colorado, where Ryan has a job in network security for the University of Colorado. Jacob and Jaiden are in a 2-days-a-week program at the local school to provide enrichment for home schoolers. For pictures of the kids. look for Ryan or Amy McDaniel on Facebook.
