One Man's Struggle with Stomach Cancer

by

Gary Richard Olson

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Introduction

Note: The original online blog, "Checking in on Gary," has been converted to e-book format for ease of reading.

In May of 2010 I was diagnosed with stage 3 stomach cancer. At that time I created this blog to keep friends and family informed of my progress throughout treatment.

The cancer treatment has been a tremendous struggle for my family, particularly for my wife Anne. The blog has been a great way of letting people know what was going on without making them feel they were bothering us with a bunch of questions.

We are particularly grateful to Anne's sister Marcia who kept the blog going while I was too sick to contribute.

I have successfully completed treatment and the prognosis is good. Though there are no guarantees, it is looking promising that I have probably beaten the cancer.

A number of people have suggested I keep the blog active even after treatment was completed. They thought it might be helpful to others facing this illness to follow the progress of someone who has been through it. They also said they liked my writing, and my humor, and didn't want to see it go away. I decided to take their advice.

Though the blog has outlived it's initial purpose of keeping my friends and family updated, I still think it may have value to those struggling with this challenging disease.

If you or your family have been touched by stomach cancer, I hope reading about my experience will offer you insights into what lies a head as well as hope.

If nothing else, I hope it helps people realize there can even be humor in something as dreadful as cancer. My prayers are with you.

1 - The Epic Story Begins

It's the C word.
May 2, 2010

This whole thing started with a case of bronchitis, that turned out to be anemia, that was suspected to be a bleeding ulcer, that is now strongly suspected to be cancer of the esophagus.

On Monday we will get the results of the biopsy that will confirm whether it is cancer or not. The doctor who looked at the thing with a tube they stuck down my throat (the Valium they used was nice) is certain it is cancer.

Sometime this week I will go in for a more sophisticated test that involves taking some kind of high tech picture of the thing. This test should determine what we are dealing with and the best course of treatment.

At this time it appears the most likely treatment will be a combination of surgery and chemotherapy, but we won't know for sure until the next round of test.

We'll keep you informed.

I had no idea I had this many friends.

May 2, 2010

I am astounded by the overwhelming support I am getting from friends, neighbors, and relatives. I had no idea there were so many people who cared about me that much.

I'm also amazed at the fantastic response I've gotten from my friends on Facebook. People from all over the world are praying for me in every variety of religion. It's all pretty amazing, and greatly appreciated.

The pathology report is done and the news is encouraging.

May 4, 2010

The pathology report indicates I have adenocarcinoma cancer which is a very common cancer that is treatable.

When the pathologists did the initial examination they saw abnormalities, but nothing that was glaringly obvious that it was cancer. As they examined further they discovered the adenocarcinoma cancer.

In other words nothing jumped out at first sight that was obviously bad news. They had to dig around to find the cancer. This is good.

The doctor says that what they are seeing may be early lesions. In other words, we appear to have caught it early. The doctor said there is good reason to be optimistic.

Some observations about my friends and life in general.
May 4, 2010

It has been fascinating watching the reactions of people when they learn I have cancer. Young people tend to be shocked and emotional because it is so foreign to them. People my own age (62) tend to become distraught realizing if it could happen to me it could happen to them. People over 70 tend to take it in stride because they have seen it so many times before.

I've been astounded by the number of people who have offered to provide transportation, food, or help with everyday chores. Some of these people have been relative strangers. You can't imagine how good this makes me feel.

I've also been gratified by the support, concern, and humor of my many Facebook friends. By having reached out to hundreds of people from all over the world I've built an international network of support. The flood of encouraging messages has been wonderful.

Many people have been concerned about how I am holding up. Surprisingly, this hasn't been an issue. With the exception of the scary parts, I have actually been quite happy. It is amazing how cancer focuses your attention on all the good things that are going on around you. It creates an uncommon appreciation for friends, family, and the simplest pleasures in life.

Cancer does have a remarkable ability to focus your attention on the good things in life. Whatever happens, it is obvious this is going to be a life changing experience. Though I am not looking forward to it, I am not dreading it either. It will be what it is going to be, and I will be a better person for having survived it.

Next test scheduled for 10 AM Wednesday May 5th.

May 5, 2010

The endoscopic ultrasound procedure is scheduled for Wednesday at 10 AM. At that time they will go back down my throat and do a more detailed analysis that will determine the best treatment. This may include a combination of surgery, chemotherapy, and radiation.

We won’t know exactly what the treatment regime will be until after the procedure on Wednesday. From there we can plan what will happen next.

Ultrasound results could be a lot worse. I continue to be encouraged.

May 6, 2010

I completed the endoscopic ultrasound procedure and the results are in. I have stage three cancer (on a scale of one to four) which is better news than it sounds.

The treatment and prognosis for the first three stages of this type of cancer are pretty much the same, so it's irrelevant whether I've got a stage one, two, or a three. Of course it matters to the doctors, but they are more into subtleties than I am.

It would be a different story if I had a stage four cancer, because then it would be time to start thinking up funny things to put on my grave stone.

The main reason I have stage three, instead of stage one or two, is because the cancer has affected the lymph nodes that are close by. The bottom line is this diagnosis continues to be really good news. Or at least as good news as cancer diagnoses get.

At 12:45 on Wednesday I have an appointment with an oncologist named Dr. Ey. At that time we will have more information and we will start putting together the treatment plan and team. Treatment will probably start within two weeks.

I'd like to thank everyone for their prayers, they seem to be working.

Anne is hanging in there too.

May 7, 2010

It has come to our attention that we have not let you know how

Anne is doing. We decided to have her write something for me to post here:

“Given the nature of the news we received last week, we are both doing better than we might have expected. It has so changed things that I find I just have to accept it rather than try to fight it.

Several things have helped with this. Most important is Gary’s incredible ability in this time to see the glass as half-full. I thought I knew Gary really well, but this experience has revealed a deep inner strength in my husband which I had never before fully appreciated. Without his strength and attitude, I would not be doing as well.

My rudimentary understanding of the Buddhist concept of pain vs suffering has been an incredibly powerful tool for me. One of the problems of any diagnosis with the word “cancer” is that it is an emotionally-charged word filled with “black” images and scenarios, many left from decades ago. Whenever my mind goes there, I try to catch myself and ask, “Is this happening now?” The answer is invariably “no,” so I realize I am suffering unnecessarily and also missing out on the present moment.

Thank you all for your prayers and support for both of us. It means more than you can imagine. Please continue to ask for the best possible outcome for Gary.”

Comments on the flow of positive energy from our friends.

May 8, 2010

I’ve never been a religious person, and am not becoming one now. But the world view that something does not exist unless it can be measured is woefully inadequate.

There is something beyond our comprehension that can only be described as God. Though I am certain I have a very different notion of what God is than many of you, I realize the spiritual aspect of this experience as something that bonds us.

The many prayers that have been directed our way have had a profound effect on both Anne and me. It is so reassuring to know there are so many of you out there sending positive energy our way.

I continue to be astounded by the warm reactions of my many Facebook friends from around the world. A few years ago it was unimaginable that Muslims from Bangladesh would be praying to Allah on my behalf. But that is what is happening. It is as amazing as it is wonderful.

It doesn’t matter whether it is the prayers of my Christian and Muslim friends, the meditative practices of people feeling bonded with Mother Earth, or expressions of warm concern from the secular. We draw strength and healing from all of you.

Both Anne and I have acknowledged we can almost physically feel the positive energy that is being projected our way. We are intensely aware of its presence and we feel it is both healing and beneficial.

We would like to say, thank you. Thank you so very much.

2 - The Power Port 4000

New information from the oncologist visit.
May 13, 2010

The good news is I don't have to undergo radiation therapy and my cancer is potentially curable, not just treatable. The news pretty much goes downhill after that.

It turns out the cancer is lower than the esophagus, which makes it stomach cancer. This means it is likely I will have part of my stomach removed surgically.

The potential upside of this is they MIGHT be able to do this with laparoscopic surgery, rather than cutting me open. Not all that big of an upside, but I'll take what I can get.

Before and after surgery I will go through nine weeks of chemotherapy. They will surgically insert a chemo delivery device into my chest. The device will be attached to a pump that will keep a steady supply of chemo chemicals pumping into my system.

I will basically wear the pump. It will be attached to my waist and have a long tube that feeds the chemicals into my system. I can't get this wet, so I have to give up my 40 minute daily swim. I'll probably replace the swim with a brisk walk. Exercise is an important part of getting well.

A new round of chemo will be administered three times over a nine week period. Each time I get a fresh jolt of chemo I'll feel crappy. When I start feeling better I'll get more chemo. The whole thing is going to make me nauseous and tired.

Though the doctor was a little vague on the specifics, it looks like I can expect my hair to fall out. I am seriously considering shaving my head and writing CANCER on my forehead so people don't mistakenly think I am one of those guys who shaves his head because he thinks it looks sexy.

This Friday, in the morning, I will meet with Dr. Cook to discuss the surgery to implant the chemo delivery system. Friday afternoon I will have a PET scan to confirm the cancer hasn't spread and to help them refine the treatment regime.

Though there is much more information that we haven’t had time to absorb, this is the nuts and bolts of what we know so far.

My biggest concern is that if my beard falls out people will realize I grew it to conceal that I have no chin. This was a secret I thought was safe. Drats!

It was a rough day, we're both wrung out, here's a quick update.

May 15, 2010

This morning we met with Dr. Cook who is the surgeon who will implant my chemotherapy port and will probably do the major surgery.

The port is a small reservoir that will be connected to an artery in my neck. The whole thing is surgically implanted and will not be visible. The chemo is administered through a tube that is inserted into the reseviour with a needle. The tube is attached to a pump, that I will wear, that pumps the chemo into the reservoir.

I will wear this contraption 24/7 for nine weeks. This will be followed by surgery. The surgery and recovery will take about two months. This will be followed by another nine weeks of chemo.

Dr. Cook did not indicate laparoscopic surgery was likely to be an option, though it is not entirely ruled out. This means major surgery is likely. The decision will be based on how much the tumor has shrunk after the first round of chemo.

Before we totally commit to this process we will be exploring other treatment options. Because the stakes are so high we want to be certain we are following the best course of action.

This afternoon I underwent a PET scan. After fasting all day they shot radioactive material into my arm and had me sit quietly for an hour until it spread through my system. They then sent me into an imaging machine.

The radioactive material is attracted to cancer, so by measuring where the material has massed they can find cancer. This test is primarily to determine if the cancer has spread.

The upside of the procedure was they allowed me to listen to Beatles music on my mp3 player during the prep and scanning procedures. That was pretty much the high point of my day.

I can't put all this into perspective because I didn't eat most of the day, am exhausted, and psychologically wrung out.

I am absolutely certain there is some humor in todays events, but at the moment it is beyond my grasp. After a good nights sleep I'm sure the humor will become apparent. But for now it escapes me.

Thanks again for all your support. I appreciate that you’re following the blog. It is important to us that so many people care.

Sleep helped. I feel much better now.

May 15, 2010

As I predicted yesterday, I am feeling much better now that I've had a good nights sleep.

I considered not posting yesterdays update because it seemed such a downer. But stomach cancer is a difficult thing and there are going to be ups and downs. Yesterday was a down.

I figure if I always post upbeat humorous posts people will start thinking I'm weirder than I actually am. Assuming that's possible. Well, come to think of it, maybe that isn't possible. But you get the idea.

I figure this is going to be an emotional roller coaster, and the blog can't help but reflect that. I'll try not to make it too depressing, but some days are just going to be like that.

A wonderful email comes from nowhere.

May 18, 2010

On Sunday I got an email, through Facebook, from a total stranger. She discovered me through a comment I posted on a Facebook wall where I referred to the installation of my port as a Borg implant. Which, of course, it pretty much is.

She was successfully treated for Hodgkin's lymphoma and wanted to share some of her experiences with Borg technology. Actually, she didn't exactly phrase it that way. But that was what she was talking about.

Since she chose to email me rather than post on this blog (which she had discovered) I am not going to post her comments. None-the-less, I am posting my response to her email since it's already written and I thought it would make a nice posting.

Consequently, the rest of this posting is what I wrote to her.

I had already figured out the medical establishment knows a great deal about science and almost nothing about healing. As much as I am dependent on their science, I am equally depending on my attitude, support system, and sense of humor to get me through this.

I am fortunate to be married to a nutritionist who is supplementing our already healthy diet with food known to enhance the immune system. For the most part, I am as healthy as a horse. I figure this will be a huge advantage.

I created the web site, at my wife's suggestion, as a way to update our friends without having to send out a gazillion emails.

I immediately saw it as a valuable tool in working through my thoughts and feelings about what is going on. There is nothing like writing about what you are going through to dissipate the fear. Particularly when you make fun of the whole thing in the process.

Your doctor was smart to not let you see the side effects of your treatment. I've learned from the internet the potential side effects of my treatment. It's not something that makes you want to paint happy faces on your toes.

I was initially concerned about my hair falling out. At this time it seems the least of my concerns. However, it is nice to hear yours remained intact, even though yours was thick and mine is thin. We'll see.

I know what you mean about the bravery thing. My wife, and many of our friends, are astounded by my positive approach, stoic attitude, and humor. They don't understand.

As you say, it's about survival. You just do what you have to do. There is no other choice.

You don't survive by whimpering, whining and crying. Though there are certainly times for all of those things. Survival depends on focusing your energy on beating this thing, and it takes too much focus to allow for the indulgence of self pity.

Speaking for both my wife and I, I thank you for your uplifting and healing thoughts. They are greatly appreciated.

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Borg chemo port insertion scheduled.

May 19, 2010

I am scheduled to have the chemo port surgically installed at 1 PM on May 28th.

It will be a day surgery procedure that involves running a tube into a vein in my neck. The tube will be connected to a reservoir (port) where the chemo is administered. This whole contraption will be under the skin.

The top picture is what the port looks like. The round part is the reservoir. Though I will be able to feel it with my fingers, the port will be under the skin and will not be visible.

Chemo will be administered by inserting a needle, which is connected to a long length of tubing, into the port. The chemo will be pumped into the port from a pump that I will wear.

The chemo treatments will begin on the morning of June 3rd.

Though the pump will run 24/7 I will go in once a week for refills. I will not be required to use the phrase “filler er up”. They will just do it with out being asked, which is very efficient.

The bottom picture is what I will look like if the surgeon gets carried away. There is minimal risk this will happen because our insurance will not cover it.

Developing a survival strategy.

May 20, 2010

“That which does not kill us makes us stronger” – Nietzsche

It’s a pretty good bet the next year is going to be an ordeal. I figure it best to approach it like preparing for a marathon. Which, considering how long and grueling it promises to be, it will be.

The goal has to be to remain as strong and healthy as possible while the medical establishment puts my body through extreme trauma. Ironically, it isn’t the cancer, but the treatment, that will be causing the physical distress.

The key factor will be keeping my immune system as healthy as possible. The best bet for this appears to be exercise, good nutrition, and possibly supplements. I’m also going to continue therapeutic massage along with other alternative immune system enhancing treatments.

I have resumed my 40 minute per day lap swim and am doing weight bearing and stretching exercises. Once the port is in I’ll have to give up the swimming, but will replace it with walking as briskly as I can tolerate.

The chemo can induce an intense fatigue that rest will not alleviate. Interestingly, aerobic exercise will combat it, assuming you can garner enough energy to pursue it. I’m going to have to find that energy.

My intention is to develop a daily plan that is fairly regimented. It will include as much exercise as I can tolerate, frequent meals whether I want them or not, drinking large quantities of water, and a daily log of my activities.

I’ll probably make the log a Category on the menu of this web site. The primary function of the log will be to keep me focused on what I need to be doing each day. It will also serve the function of publicly humiliating me if I slack off. Public humiliation is sort of an internet specialty of mine.

I suspect the most difficult aspects of cancer treatment is the psychological challenges of getting through it. I imagine the physical fatigue, monotony, and excessive length of treatment will be dispiriting over time.

I'm going to continue seeking out ways to have as much fun as I can during the ordeal. Actually, there is a chance I might not react too badly to the chemo. There will probably be times that I feel fine, or as fine as you can feel when you are wearing a fashion accessory involving a tube attached to a sump pump.

I've decided, during the times when I really am laid up, to watch the entire “Lost” TV series from the first episode to the last. Since they are available from Netflick I'm going to watch the whole thing in sequence.

That way, when I go to parties, I can make small talk about topics that were hot four years ago. It will preserve my aura of social ineptness. Usually I don't have to work at this, but this time I am making an exception.

And, of course, through all of this, I will continue to do my part to perpetuate weirdness on the internet. Because, this too, is something I do. And I do it so well.

Not a hero, but a clown.
May 24, 2010

Life has handed me an epic story.

A heroic life and death struggle against formidable odds in an unfolding drama with lots of potential twists and turns. Plot lines don't get better than that. It is a story I can't resist telling.

Yet there is an aspect of the story people don't seem to understand. I'd like to set the record straight.

People comment about how well I am handling the situation, what an inspiration I am, implying I am a some sort of Viking hero. Nothing could be further from the truth.

Don't get me wrong. I love all the positive things people are saying, I thrive on it. But the truth is I'm just a guy getting swept along by events.

I am merely coping the only way I know how. By invoking my inner clown, putting on my silly hat, letting out a chuckle, and making fun of life.

There is nothing heroic in what I am doing. Being a hero involves making a choice. I have no choice here.

An example.

The men stand at attention, the colonel says "I need a volunteer to parachute into Nazi Germany, assassinate Hitler, walk 200 miles through enemy territory, blow up heavily fortified military installations as you go, seduce glamorous female resistance fighters, and be back in time to perform open heart surgery on little Timmy, the generals only son”.

Steve McQueen saunters forward and says “I can do that, I’ll volunteer.”.

Now that’s a hero.

That is so not me. I would not volunteer. I would hold back knowing that if I went I would not be up to the task. Not even the task of seducing the glamorous female resistance fighter, which is the easy part.

No. Given a chance, I’d run like hell. Because, truth be told, I am no hero. If I could run now I would. But I can’t.

So I struggle through this difficult situation not by being a hero, but by finding humor where none exists. I do this because I am not a hero but am a clown. That is just the way it is.

Today’s pre-surgery appointment went well.
May 28, 2010

We went in for the pre-surgery appointment today. It went very well. We met with a nurse who explained a lot of things, which was very helpful. I am feeling much better about the entire course of treatment because of it.

We talked some about tomorrows installation of the port, but we also discussed the overall course of treatment.

It’s still going to be a long haul, but some of my concerns have been alleviated. The chemo is going to be whatever it is going to be. However, when it’s time for the major surgery, probably sometime next Fall, it’s probably not going to be as awful as I was anticipating.

For one thing, they’re big on pain management so the level of discomfort will be quite manageable. They see pain as inhibiting recovery, so they want to minimize it. I can get on-board with that.

They will also have me up and about almost immediately after surgery, so I won’t be languishing in a hospital bed. This appeals to me a great deal, at least it does now. I might not be so hot about the idea when I’m fresh out of major surgery. But I’ll get over it.

Anyway, that’s a long time off.

Tomorrow, Friday, at 1 PM I will have the surgery to install the port. I won’t be out of surgery and ready to go home until at least 4 PM.

When the surgery is over I won’t have eaten anything for sixteen hours and will still be groggy from the anesthesia. I will not be operating any heavy equipment.

Since I’m not going to be at my sharpest, I probably won’t be able to post an update until Saturday.

At that time I hope to be able to tell you what it was like becoming a Borg.

I have joined the Borg collective.
May 29, 2010

The Borg port is installed.

The worst part was going without food for fourteen hours prior to the surgery. The best part was the warm glow immediately following surgery. Thank you pharmaceutical industry.

Today my shoulder is sore, I am fatigued, and I feel generally crappy. However, for the most part, it's not that bad.

Just don't expect me to jump up and say "Tennis anyone?".

In case you were thinking of buying yourself one of these gizmo's, the brand name is PowerPort. They come complete with a key ring, ID card, and a check list. None of these accessories appears to have any practical application.

The product also has it's own motto, which is "Feel the New Standard of Care". Considering how sore my shoulder is, and how crappy I feel in general, they might consider firing the marketing people that came up with that motto.

I'm thinking if you're going to have a snazzy name like PowerPort you should stick a number on the end. Preferably a large one. Something like PowerPort 4000.

Everyone would instantly know someone with a PowerPort 4000 is more manly than some guy driving a Ford 150 truck, for example. After all, anything rated 4000 is way more masculine than something rated a mere 150.

Unless, of course, the Ford 150 has a winch. Which would be a whole different matter entirely.

The best part of leaving the hospital is they give you party favors. My favorite was a clear plastic barf bag marked with numbers so you can measure exactly how many ounces you hurled.

I’m not sure how I’m going to use this, but I’m sure it’s going to dramatically improve my social standing. If this doesn’t make me popular, I don’t know what will.

Video telling YouTube friends about cancer.
June 2, 2010

I created this video to tell my friends on Youtube about my cancer diagnosis. I figured I'd also post it here because it is relevant to the site, even though it doesn't say anything you don't already know.

3 - Picard, The Chemo Pump

Thursday it all begins.
June 3, 2010

At 9:15 Thursday morning I begin the chemo process.

At that time I will be meeting with Dr. Ey, my oncologist, to discuss the details of what I am about to go through. I will then be seated in a comfortable chair and for the next three hours have chemo pumped into my system.

After that I'll be outfitted with the pump that will be injecting chemo into my system 24/7 for the next nine weeks.

The adventure begins.

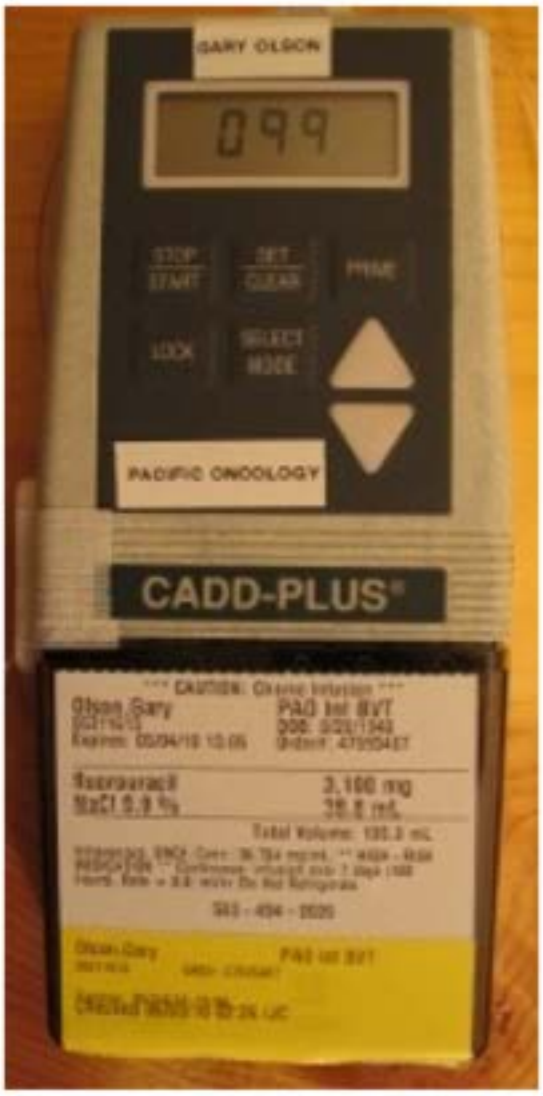
Chemo pump needs a name.
June 4, 2010

I officially started chemo today.

It turns out, for the most part, the side effects of the chemo don't start for a couple of days. On Saturday I could start feeling it, then feel awful for a few days, but start feeling better sometime on Monday.

Or, I might be one of the lucky ones who don't experience side effects. We'll find out soon enough.

The picture below is of the chemo pump. Obviously the first priority is to come up with a name for it.



It cannot be named Sally because that is already the name of my sister-in-laws truck. And it can't be named Fred or Ethel because that is the name of the ducks who have visited our yard every year for the past 15 years.

I am going to need help in coming up with an appropriate, or inappropriate, name for the thing. I am hoping you will have suggestions.

As to the chemo experience, I spent four hours in a LazyBoy recliner having anti-nausea and chemo drugs fed into my body. Other than being a little light headed and tired I didn't feel a thing. The place wasn't very crowded and by the end of the four hours I was sort of enjoying the experience. Sort of.

I am already very glad I had the PowerPort 4000 installed. Not having a needle and a tube permanently in the arm makes for much greater mobility. It's still annoying to have a tube attached to the chest, but it's much easier to get around than when it's in your hand.

The pump-with-no-name is smaller than I thought it might be, so that was a relief. I was once on a 48 hour heart monitor that was similar, and it was tolerable.

Anne and I met with Dr. Ey and later with one of the Chemo nurses. Between the two of them we received an overwhelming amount of information. Anne took extensive notes and I shook my head and said “Uh, huh” while pretending I was tracking it all.

If I didn't have Anne keeping track of all this stuff, getting things scheduled, and creating a plan of action I'd be totally overwhelmed. I'm getting all the credit for having such a positive attitude, which basically involves my continuing to be a smart ass. Anne is the real hero of this saga. She is the one making this work.
Without her I would be in so much trouble I can't even imagine how bad it would be. Thank God for the “for better or worse” clause in our contract. I'm so glad we didn't have it stricken from the agreement because it's really paying off now.

In a phone call from my cousin John he made it clear that if I lose all my hair the family is NOT going to be shaving their heads in support. That's OK, I wouldn't shave my head for them either. Perhaps as a compromise they could toast to my health with a beer, or two, or three.

I'd do as much for them, assuming it was good beer.

The Borg exposed.

June 6, 2010

The picture below is of a Borg initiate without his rubber jump suit. If the Federation had seen this picture they would have stopped fearing the Borg.

The picture has a vague similarity to what I look like with the PowerPort 4000 and “pump that still has no name”. I hear rumors there are still more pump name suggestions out there, so I’m waiting to hear them before making a final decision.

Dr. Ey predicted I would be feeling the effects of the extra intense dose of chemo I got on Thursday by later Saturday, which it now is. So far I feel fine. Not great, mind you, but fine.

Yesterday I received acupuncture and herbal remedies specifically for alleviating the side effects of chemo as well as boosting my immune system. So far they seem to be working.

I’ve started a fairly intensive program of exercise, drinking large quantities of purified water, relaxation exercises, chemo symptom monitoring, herbal supplements, and eating a carefully managed diet. It’s quite a regimen.

Every week I go back to have my blood drawn for analysis through the PowerPort 4000 and my 24/7 supply of chemo replenished. Three weeks from my first chemo treatment I go in for another super chemo blast.

There are differing opinions about whether all of my hair will eventually fall out. Some seem to think it will only thin, others think it will all go.

The nurse who administers the chemo is of the “it will all fall out” school of thought. I told her of my plans, if that happens, to have CANCER written across my forehead so no one mistakenly thinks I’m one of those old geezers who shave their head because they think it looks sexy.

She laughed. I figured she may as well start getting used to me early on.

The 1st super duper chemo treatment.

June 8, 2010

Every three weeks I get a super duper chemo treatment that is substantially more intense than my ongoing 24/7 routine. This weekend was the first of those treatments.

I was repeatedly cautioned that these treatments would be unusually nasty and likely to lay me low for days. They couldn't predict exactly what would happen, but it was not going to be pleasant.

This weekend I completed the first of these mega treatments and the complications were quite tolerable.

Rather than major nausea that left me bed ridden, I found it uncomfortable swallowing. The lower GI track problems never materialized. Though the experience wasn't entirely pleasant, it was tolerable.

In fact, I would say it fit the category of the "best case scenario".

I am fairly confident the minimal side effects were due primarily to my trying acupuncture and Chinese medicine. The doctor, nurse, and information I have read all indicate acupuncture is helpful in relieving symptoms.

More significantly, this opinion was confirmed by our dog.

After our dog Molly had her back surgery she was wobbly and had difficulty walking. We had heard of people who had successful experiences with acupuncture on their pets. I was skeptical. But we decided to try it.

To be scientific, and to avoid the placebo effect, we did not tell Molly prior to her treatment that she would be able to walk better after her session. The fact Molly is deaf created a “double blind” research model because she could not hear stories from other people or dogs about the effectiveness of acupuncture.

This effectively eliminated the placebo effect. She would not feel better because her subconscious mind convinced she would because of what she had heard.

To my surprise, Molly’s ability to walk and run comfortably significantly improved following her acupuncture treatments. The effect wears off after a couple of months, but we just get her another treatment. So far it has worked almost every time.

I know some of you are skeptical about this. And in fairness, there is a slight chance this was not as scientific as I implied. There is a possibility the placebo effect did take place because Molly had prior knowledge of the benefits of acupuncture.

After all, I can not totally guarantee she had not learned about acupuncture prior to treatment from reading the newspaper or surfing the web.

The pump has a name.

June 9, 2010

After much agonizing, I have chosen a pump name.

It is “Picard”.

Congratulations Candace. You’re suggestion has been selected.

I didn’t choose Picard out of a love for Captain Jean-Luc Picard, or Patrick Stewart, but because Picard was the only adult male human to ever be assimilated by the Borg and manage to break free of the collective.

With all due respect to the life saving characteristics of my pump, I want to be free of it as quickly as possible. Picard freed himself from the collective, and someday so will I.

Therefore, “Picard” is by far the name that best represents my relationship to my pump. A relationship to be terminated as soon as is feasible, because resistance is NOT futile.

I want to thank everyone for their suggestions. They were all excellent.

An issue I had with many of your choices was that they were too affectionate. Though I appreciate the lifesaving characteristics of the pump, I have no warm fuzzy feelings towards it.

I definitely do not consider the pump a buddy or a pal.

No device that requires that I duct tape saran wrap to my chest in order to take a shower will ever be my friend.

Picard gets a refill.

June 10, 2010

Wednesday we took Picard in for a fill up. He’s now loaded with fresh chemo for another week of 24/7 cancer killing action.

While we were at Pacific Oncology we learned from my blood work that I was dehydrated. In spite of drinking massive quantities of water, the chemo had depleted my fluids.

I agreed to spend an additional two hours having an IV drip add more fluids to my system. It was worth every minute of it. The extra juice cleared by brain, lessened my fatigue, and made it easier to swallow.

To celebrate we went out for a steak dinner. It was the first thing I’d eaten in days that was more substantial than soup.

It was wonderful.

We also learned the chemo was going to make my skin extremely vulnerable to sun burn. I am going to have to wear protective head gear and have all my skin covered even in moderate sunlight.

Unfortunately, this also means my body is going to have to be fully covered during the hottest days of summer.
This shouldn’t be too much of a problem as long as I wear something that is loose, flowing, and allows for a lot of air circulation.

Fortunately, I live in liberal Oregon where no one gives a second thought at seeing a 62 year old man wearing a flamboyant sun hat and a Moo Moo.

The challenge of summer clothing.

June 13, 2010

When you're six foot three, and 200 pounds, buying clothes is a huge challenge.

I'm too big for regular sizes but too small for "Big and Tall". Regular size shirts won't tuck in and look goofy left untucked. Regular shirts that come in "Tall" work, but very few manufacturers offer them.

I eventually resigned myself to the fact that LL Bean was the only company that sold tall shirts that look good on me.

The upshot is I've been wearing the exact same style of shirt for twenty years. This has been a source of frustration for Anne. Every day, decade after decade, she's looking at a husband wearing the same shirt. Monotonous.

But what could I do?

Now I suddenly discover, with summer peeking around the corner, the chemo requires I wear long sleeve shirts during the most blazing heat. This is not only going to be uncomfortable, but dweeby.

For twenty years I haven't been able to resolve my clothing dilemma. Now I have a matter of days to find a solution. I am desperate.

The answer comes from Linda H (not to be confused with Linda G) who facetiously suggests I wear "Arab" clothes. At first this seemed a marginally better suggestion than my idea that I wear a Moo Moo.

However the more I looked into it, the better the idea sounded. After all, in the Middle East they've managed to stay cool while fully covered for centuries.

The picture on the previous page is of the Hafid Top that I have ordered from the Shukr Closing Company. It looks nice, has long sleeves, and will protect me in the hottest days of summer.

The perfect solution.

Picard gets another refill.
June 16, 2010

We took Picard in for his weekly refill and to get my blood tested.

My white blood cell count was a little low. This means I shouldn't shower in the sneeze of someone with a bad cold. Which is not something I normally do anyway.

The low white blood cell count wasn't low enough to force me to hide from society like a deranged hermit with an obsessive fear of random viruses. We're saving that for another day.

I have had a minor mouth sore, which I frequently get when I eat too many pineapples and oranges. Which I have done recently.

The folks at Pacific Oncology conceded it was probably not from the chemo, but they weren't sure. To be on the safe side, they gave me a graphic description of what mouth sores from chemo are like.

They are roughly like being a leper, with the sores of Job, who has been hung by an angry vigilante group who haven't watched enough Westerns to know how to tie a proper noose.

Oh Ok, I exaggerated on that one a little bit. Well, maybe a lot. But that's how it felt hearing their description.

We’ve figured out these folks make extra efforts to be sure you’re warned about the worst possible scenario. Which is good, but unsettling.

We now know what we are potentially up against and have the preparations in place to deal with it. However, we are not rushing into a panic.

So we’re all set until next Wednesday when I get my second Super Duper chemo treatment.

You can imagine how excited I am about that.

A six day vacation from Picard.

June 22, 2010

We had been planning on getting away for a few days to our house in LaGrande.

A few days before we intended to leave I developed a mouth sore. This didn't particularly concern me because I often get mouth sores after eating a lot of pineapple and oranges, which I had recently done.

The folks at Pacific Oncology weren't particularly concerned either, at first. Though severe mouth sores are a potential side effect of chemo, they thought it was OK since I get these sores all the time.

The next day, when I got a second sore, they became very concerned.

So concerned that they DISCONNECTED ME FROM PICARD.

Now to anyone else this might be like "Oh, that must be nice for Gary". For me it was like "OH MY GOD!!! I'M FREE FROM PICARD FOR SIX DAYS!!! IN LAGRANDE!!! FOR SIX DAYS!!! I'M FREE!!! HOORAY!!!".

In other words, I was quite pleased.

They set me up with two kinds of super duper mouth wash in case I had any further problems, then sent us on our way.

We just got back yesterday. It was a wonderful vacation.

Well, as wonderful as it can get when you have the cancer cloud hovering over your head. But it was wonderful none-the-less.

On Wednesday I will get reconnected to Picard. I'll be at Pacific Oncology all day since this is my day for the next super duper treatment.

Since my symptoms from the last super duper chemo blast seem to have stemmed from dehydration, I will be going back in on Friday to get additional IV fluids. With luck, this will eliminate the problems I had last time with swallowing.

It's amazing how many calories chemo burns. To keep from losing too much weight it is necessary to dramatically boost calorie intake. This has the effect of converting eating lots of ice cream from being a vice to a virtue.

I am being very virtuous. I am planning on being even more virtuous in the near future.

Bonus Days – Another week without Picard.

June 23, 2010

The super duper chemo treatment that was scheduled for today got postponed for a week.

It seems my white blood cell count is still a bit on the low side. Not low enough to cause me to be ultra vulnerable to viruses, but low enough to be of concern.

The concern isn't how low the count is, but how low it would probably become after the super duper chemo treatment. If it gets too low the possible side effects could be wickedly nasty.

Dr. Ey decided it would be prudent to postpone treatment for a week. This will give the white cells a chance to breed, or whatever it is white blood cells do to multiply. Whatever it is, I hope they are having a good time.

Apparently the low blood cell situation happens fairly regularly. It is not considered a problem and does not interfere with the effectiveness of treatment.

Of course, the really significant thing is they didn't hook me back up to Picard. I am a free man for another week. This is mighty darned nice.

Next Wednesday I get the super duper chemo treatment after getting Picard re-connected, followed by a special shot on Thursday, followed by getting IV fluids on Friday.

That "special shot" costs $6000 a pop. Which does make it pretty special. Thank goodness for insurance.

I am assuming the shot is so expensive because it contains dandruff accumulated from the wing tips of endangered Amazonian butterflies that must be collected at the stroke of midnight by PhD botanists who have received advanced trained at Johns Hopkins University.

My understanding is Amazonian butterfly dandruff has amazing healing powers, which could account for the costs.

Either that or there’s a huge profit margin for the shots and pharmaceutical stocks are about skyrocket.

I’m betting it’s the butterflies.

Fu Man Chu and hair loss.

June 24, 2010

There are a lucky few who get through chemo without losing all their hair. I was hoping to be one of them. It’s not going to happen.

I have this habit of running my fingers through my beard. About a week ago after doing this I noticed my fingers were full of beard hair.

Not good.

Every day since then I’ve noticed when I brush my hair I release significant quantities of hair. Also whenever I shower the drain gets clogged with hair.

This is really not good.

When I talked to Dr. Ey about this he said I could expect to lose my hair, beard, eyebrows, and possibly eye lashes.

I can live without the eye brows or eye lashes, but I’m really going to miss the beard. When you’re know as “the bearded one” losing your beard causes significant identity issues. I guess I’ll just have to re-invent myself.

What is interesting is the hair loss seems to be even, rather than coming out in clumps. Apparently the hair and beard will thin until my entire head looks like a very bad comb over.

That’s the point where the clippers come out.

What is interesting is there will be some hair that won’t fall out out until later. It appears that the eye brows and the mustache will be the last to go. At least I’ve seen no signs that I’m losing either of them yet.

So what I’m going to try to do, once it’s time to do the big head and beard shave, is retain a Fu Man Chu mustache.

I included a picture of Fu Man Chu with this post for those of you who are not familiar with the style.

Once the mustache goes, of course, I'll have to go with the totally hairless look.

I can guarantee you my hairless look will not be turning the heads of the senior citizen crowd the way Jean Luc Picard does every time he graces the silver screen.

It is not my destiny to become the next bald stud muffin. I'll be lucky if I don't end up looking like a lumpy bowling ball.

Fashion Update: Anne's Aunt Dorothy saves the day.

June 28, 2010

I figure if you can't have fun with cancer, what's the point of having it?

When I learned the chemo would prevent me from going out in the sun unless I was fully covered, it created a fashion crisis. What to wear?

I figured people in Arab countries have been going out in the sun fully clothed for centuries, so I turned to them for ideas.

The outfit in the picture below is what I came up with.

The top is a Jamal Shirt from the Shukr Clothing Company. The pants come from a company specializing in UV protective clothing. We thought the two went well together.

The real fashion crisis came when I'd figured out the shirt and pants, but couldn't come up with an appropriate hat.

I didn’t want to wear one of those Arab cloth-wrapped-around-your-head thingys. That was a bit too exotic, besides they looked hot.

That is, hot in the temperature sense of the word, not in the Tom Cruise before he went over top kind of hot. There’s no immediate danger of my becoming that kind of hot.

I figured a Panama style hat would look goofy. I wasn’t coming up with any better ideas. I was totally frustrated, exasperated, and stuck.

Then from out of nowhere a package arrives from Anne’s Aunt Dorothy containing the perfect hat. She didn’t even know I was desperately looking for a hat. She just sent it.

We think they all work perfectly together.

So I owe a debt of gratitude to Anne’s Aunt Dorothy. She rescued me from fashion oblivion with an astoundingly timely gift.

Thank you Aunt Dorothy.

4 - Two More Super Dupers

Super Duper Chemo – Round Two

July 1, 2010

I wrote a blog post after my first Super Duper Chemo treatment saying I was so wrung out I couldn't find any humor in the situation.

I speculated that after a good nights sleep I would probably feel a lot better and be back to my old self. The next day I posted a follow up posting relaying that I was feeling much better. The good nights sleep had worked.

Today I had my second Super Duper Chemo treatment. I'm fatigued, like before, craving a good nights sleep, like before, but am feeling much better about the experience.

This is partly because the process is becoming routine. It is also partly because there was good news from the blood work. My white blood cell count is almost back to normal and my red blood cells are in much better shape.

When my blood cells are happy, I am happy.

This good news means I don't have to go back tomorrow for the $5,999,99 shot.

The down side is that if I'd gotten the shot I'd know what it feels like to be a rich person.

Would all that expensive juice flowing through your veins make me crave caviar or cause me to to invite Phil Knight and Paul Allen over for a Budweiser?

This is something I've always wondered about. Now I'll never know.

Of course drinking beer with Phil and Paul would probably be similar to getting stuck in the chest with a dull needle. Since I already know what that feels like, maybe I'm not missing much.

Another good thing is they changed the Super Duper Chemo mix so my side effects should be easier to deal with. I will also be going in Friday morning for a two hour IV fluids drip which should eliminate the dehydration that appears to have contributed to my symptoms last time.

All-in-all, things are looking pretty encouraging.

I'll let you know how it goes, but this has been enough for today. It has been a long, tiring, brain numbingly fatiguing day.

I am going to bed.

I got the big $5999.00 shot after all.
July 4, 2010

On Friday I got my $5999.00 shot. I blew it, at least in terms of faking being a rich guy.

I was going to use it as an opportunity to savor the ambiance of the wealthy. I would nonchalantly say something like “a $5999.00 shot? Let’s play it safe. I’ll take three.”

Instead I said “The doctor said he wasn’t going to order that, you’d better double check. And while you’re at it, confirm it’s been pre-authorized by the insurance”.

So much for casually pretending spending $5999.00 to have a needle stabbed in my stomach wasn’t something that I didn’t take notice of.

I guess I won’t be sharing that Budweiser with Phil Knight and Paul Allen after all. I obviously haven’t got this wealthy guy attitude down pat.

Probably never will.

It turns out the big bucks shot is for building white blood cells. It does something to the bones to make them produce extra cells.

The doctor ordered the shot as a preemptive thing to make sure I have plenty of white blood cells in reserve. This is because I had a low blood count after the last super duper chemo treatment.

They said the shot might have the side effect of making my bones hurt the next day. Didn’t happen.

While at that appointment I also got my extra IV fluids, hoping it would reduce the side effects of Wednesday’s Super Duper Chemo treatment.

It seems to have helped.

I don’t feel great, but I can swallow. Swallowing is good. Swallowing is very good.

I’m looking forward to the July 4th party tomorrow. I should be feeling even better by then.

It will give me a chance to appreciate swallowing even more.

Chemo is turning me grey, sort of.

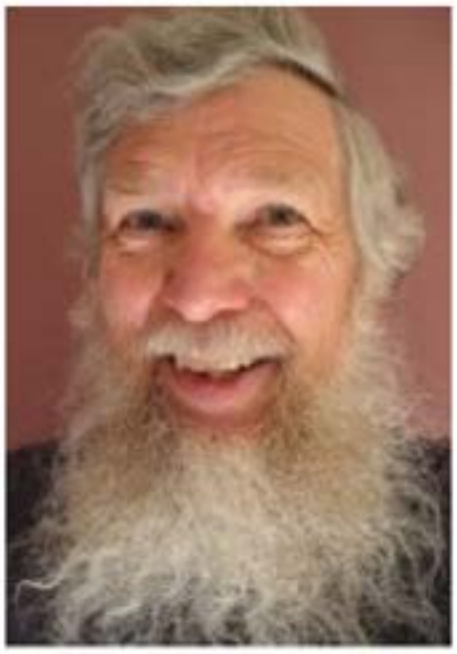
July 4, 2010

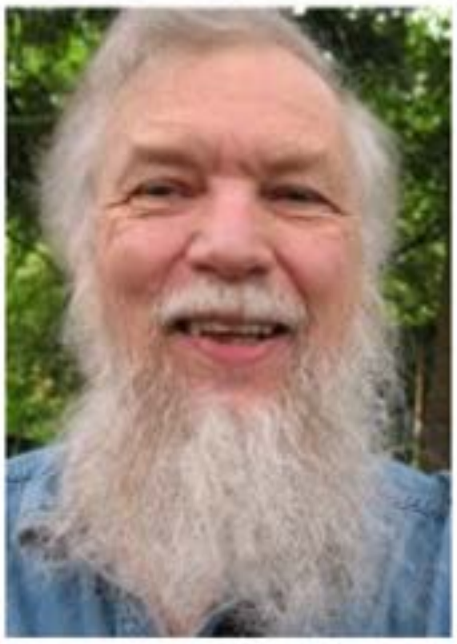
The chemo is turning me into an old man. No, wait. I already was an old man. The chemo is just making it more obvious I am an old man.

Drats!

Anne pointed out the chemo is causing my darker hair to fall out before the grey hair.

The pictures below clearly show this is true.





The picture on the top was taken before the chemo, the picture on the bottom was taken recently. It's obvious I look a lot grayer in the bottom picture. Anne was right. It also looks like I needed a hair cut on the top picture but not in the bottom one. I had originally needed a hair cut in both pictures, the bottom one just took care of itself.

As you can imagine, I get no sympathy from my balding friends. There attitude is something akin to “It’s about time”.

Who can blame them? I’ve been going around flaunting all that hair. No wonder they feel a sense of cosmic justice.

They have a point.

Now I’m asking advice from balding guys who just went ahead and shaved their heads. It’s something I have no experience in.

Many (very many) years ago I shaved my face with a razor. I’ve never shaved a head. I’m not quite sure how to proceed.

It would seem an electric razor would be the most practical. But what do I know?

Do you have any tips on head shaving? I’d love to hear them.

Picard gets another refill.

July 8, 2010

In about three days I will be half way through my first nine weeks of chemo. So far it has gone better than I ever dreamed.

Perhaps dream is the wrong word, unless it's dream as in nightmare. But as nightmares go, this one has gone really well.

We went in today to have Picard refilled. I mentioned to Joanne, the nurse practitioner, that compared to the dreadful stories of possible side effects that I'd heard my impression was that I am doing quite well.

She agreed. She even went so far as to say she thought my treatment is going "extremely well". It would seem my progress is going much more smoothly than what she usually encounters.

That was a real morale booster.

Though the super duper chemo treatments are challenging, my body is handling them with minimal side effects. The primary problem is the chemo leaves me very dehydrated. This requires that I get lots of IV fluids.

From now on when I have the super duper treatments I'm going to get IV fluids two days after the treatment, then again two days after that. This should minimize the side effects even more.

Which certainly works for me.

Dr. Ey had mentioned previously that the way my body reacts to the treatments now will probably be consistent with how it will react later on. So if I can get the side effects under control now, they'll probably remain under control from now on.
Or at least that's what we're hoping.

Another piece of good news is the $5999.99 shot worked! My white blood cell count shot up by a huge margin. I'm probably immune, for the time being, to any virus crossing my path.

This will come in handy if aliens from outer space infect Earth with a deadly virus. Not only will I have the white blood cells to fight off the virus, but will also have the prior authorization from my insurance company to get another planet saving shot.

This means that I'm destined to be a super hero. Of course that depends on aliens infecting earth with a deadly virus, which might not happen. But you never know.

I was extremely pleased my symptoms following the super duper chemo treatment were mild enough to allow me to enjoy our annual July 4th Pot Luck.

This was made possible by Ed, Lisa, Nancy, and Linda volunteering to help set it up and clean up afterwards. Though I felt well enough to attend, I totally lacked the energy to do more than that.

I spent the morning resting, took a hit of caffeine before the party, and collapsed afterwards. But I was able to attend and have a fantastic time. It is so wonderful to have good friends than come through in a pinch. We are eternally grateful to our friends for making it possible to continue this holiday tradition. Thank you.

Another week of good news.

July 15, 2010

We went in to get Picard refilled again. My blood work was great. The red blood cell count is back to normal and those pesky white cells are still looking good.

Those $5999.99 white cell booster shots seem to do the trick.

I wonder if those shots do the same thing for brain cells? Naw. Looking back over the past week they obviously don't.

My iron levels are also looking good. The iron pills seem to be doing their job. Which is nice.

So I'm all set for another week. Next week I'm due for another super duper chemo treatment. Which is always a challenge

However, this last super duper treatment was more tolerable. So we're hopeful our side effect management strategies will continue to be effective.

For some reason the hair loss has slowed down. I've definitely got that "guy in cancer treatment look", but it's not quite to the point where I'm ready to shave the whole thing off.

Maybe next week.

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We were in La Grande for the past week. We kicked back and it was very restful. I’m feeling better than any time since I started treatment.

The folks at Pacific Oncology continue to comment on how well I am doing. It’s nice to have them confirm our assessment of how things are going.

I am now over half way through the first round of chemo treatment. We have a pretty good idea of what future chemo will probably be like, so it is less daunting.

Of course, coming up next on the agenda is stomach surgery.

That’s going to be a whole other story.

Third Super Duper Chemo Done.

July 22, 2010

Yesterday I had the third round of super duper chemo. This will be the last super duper one for the first series. After this, I will have several more Picard refills to do, then I'll be done with round one.

Then comes surgery, another nine week round of chemo, then I'm done.

The appointment with Dr. Ey on Wednesday went well. He agrees with Joanne, the nurse practitioner, that things are going really well.

He attributes this to my overall good health when I began, my diligence in staying healthy during the process, and dumb luck.

He didn't give any credit to the acupuncture or Chinese Medicine. Which is to be expected.

My blood work continues to be very positive. On Friday and Monday I will be going in for IV fluids since this seemed to help alleviate symptoms.

Also on Friday I'll get another $5.999.99 shot to boost the white blood cell count. Those white blood cells are greedy little buggers. It's like extortion. They are demanding "Give us the shot or we're out of here".

Fortunately, they're extorting the insurance company, not us.

As to how I'm feeling after the supper duper chemo. I feel crappy.

These super duper chemo treatments leave me totally wrung out. They leave you feeling about as sick as you get with a bad cold. Which isn't all that bad, but not pleasant.

The first day or so the medication makes it difficult for me to think clearly. During these times Anne keeps a close eye on me to make sure I'm doing everything there is that I need to be doing. Which is considerable.

I'm not having problems swallowing yet, but the thought of eating is pretty unappetizing. I'm hoping tomorrows IV fluids will take care of the swallowing issue.

I figured I'd end with a short piece of advice.

If anyone ever recommends that you try chemo as a recreational drug, don't do it.

Slice and dice – choosing a surgeon.

July 22, 2010

Now that I'm nearing the end of the chemo it's time to give serious thought to a final choice of a surgeon.

We've already narrowed it down to two. Dr. Cook and Dr Tseng.

Dr. Cook is a traditional surgeon who operates by opening you up with a sharp kitchen knife then removes the cancer using a pocket knife and an ice cream scooper. Technically that might not be exactly how he does it, but it gives you a general idea.

Dr. Cook installed my Port. He did a very nice job. Nice clean incision and no complications. Everyone says nice things about him and he seems to be an excellent surgeon.

Dr. Tseng specializes in Laparoscopic surgery. In Laparoscopic surgery they cut a hole in you and insert a garden hose with a camera, key chain flash light, shop vac, and Swiss army knife attached. Once again, this isn't exactly the equipment they use to do it, but the principle is the same.

An advantage of traditional surgery is that when they open you up there is a big cavity to peek into. They can borrow a high power flashlight from one of those guys who inspect sewers and take a really thorough look for cancer.

With Laparoscopic surgery they are working through a narrow tunnel so it's pretty much what you see is what you get. Because there is a chance you might miss something, Laparoscopic surgery is somewhat controversial. Particularly with older doctors who don't know how to do it.

The biggest advantage of Laparoscopic surgery is they do it without opening you up. That way it is less traumatic to the body and you heal significantly faster. A shorter hospital stay is appealing.

Laparoscopic is a much more difficult surgery to perform, so you spend more time on the operating table. However, I don't care much because I was planning on sleeping through the whole thing anyway.

We haven't met with Dr. Tseng yet but have a visit scheduled within a few weeks. After that we should have enough information to make a decision.

We'll probably make the decision by having a poll on this web site. That way we'll have someone else to blame if something goes wrong.

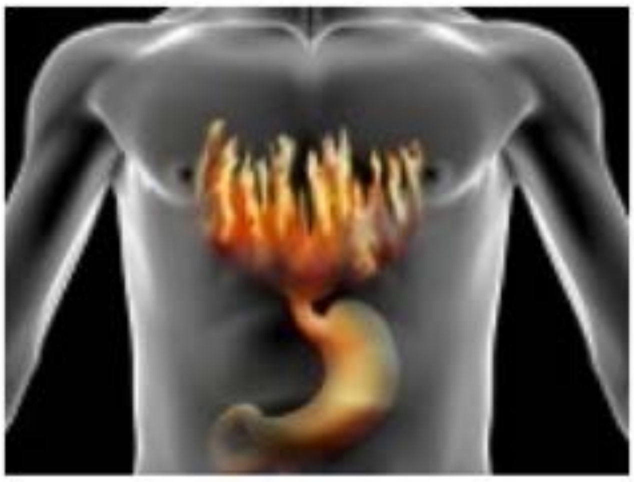
Super Duper Chemo can get nasty.

July 26, 2010

There are times in this treatment process where it's difficult to find much that is funny or even amusing. This is particularly true after the Super Duper Chemo treatments.

Since the Super Duper treatment last Wednesday I've felt pretty awful.

I'm not going to go into details because there's no point. But I figured I'd point out that, in spite of my generally positive attitude, I'm not totally laughing my way through this experience.



For the past few days I've been laid pretty low by the big chemo, which explains why I was slow to respond to comments.

I got IV fluids today and am feeling better. I am planning on feeling even better tomorrow.

While I've been laid low I've been plowing through the DVD's of the first five seasons of "Lost".

I just finished season three.

That's a lot of "Lost" to absorb in a relatively short period of time. I hope it doesn't cause brain damage.

I'm prepped for the alien invasion.
July 29, 2010

As I mentioned previously, if aliens infect Earth with a deadly virus a high white blood cell count could immunize me from their dastardly intentions. Being immune I would be free to mount a super hero offense, saving humanity.

I am ready.

A normal white blood cell count is between 4.4 and 11.0. After my last $5999.00 super shot my count us up to an eye popping 21.8.

I am invincible. Bring on the virus.

I am now completely over the nasty side effects of my last Super Duper Chemo treatment. Now I'm just living with the annoying fatigue of the Picard refills. But those are almost done.

There is only one more Picard refill to go, then he gets disconnected on August 11th.

Surgery isn't going to be scheduled until sometime in mid September, so I will have about a month off.

Well, I sort of have a month off. I still have to get an endoscopic ultrasound and a PET scan. Both require fasting and are less that pleasant, but they are endurable.

The ultrasound is so the surgeon knows how much the tumor has shrunk so he has a better idea of what he is dealing with. The PET scan is to confirm the cancer hasn't spread and the surgery is still worth bothering with.

During that time before surgery I intend to crank up my exercise program to get as fit and healthy as possible. Hopefully that will enable me to get through the surgery and recovery with minimum of hassle.

Once that is over, it’s just another nine weeks of chemotherapy and I’m done.

Piece of cake.

Yea, right.

5 - The Build-Up

Dr. Tseng launches me into the future.
August 4, 2010

God I love big boys with toys.

And Dr. Tseng, the surgeon we interviewed today, has all the other boys with toys beat. No mere cool black helicopter or Maserati for him. He uses a robot, which you can see below, to do surgery.

How cool is that?

Pretty cool. And Dr. Tseng is pretty cool himself. Both Anne and I were extremely impressed by him and his skills. This guy is a genuine hot shot surgeon.

Unfortunately, when it comes to the actual surgery itself it doesn't cause you to want to dance on your happy feet.

The good news is he can do the surgery without slicing me open like a gutted fish.

And it's also good news that the robot surgery is far more sophisticated than the old fashioned laparoscopic surgery. And it's also good news that the recovery time from this surgery is considerably better than traditional surgery.

In fact, if all goes well, I'll be out of the hospital in a week. And, though I'll be very tired, I won't be in any pain once I go home.

But the good news pretty much stops there.

What we didn't realize was this form of cancer requires my whole stomach be removed and replaced with a smaller stomach which he builds from spare parts. Actually they're not exactly spare parts, more like other parts of my guts that will be re-purposed.

Of course re-purposing is very trendy in this age of recycling, but the idea didn't leave me feeling all warm and fuzzy.

The bottom line is we're talking MAJOR surgery here, and the chance of complications is significant. However, if there are no complications I should experience a minimum of post surgery discomfort. Which is good news.

Then again, if when he starts the surgery he finds additional cancer lower down he's going to bag the stomach rebuild and call it a day. Which means I will also be calling it a day around six months down the road.

Odds are that's not going to happen. But it is a risk.

After the surgery they'll do a biopsy on the guts that were not recycled. That should confirm how bad the cancer was, giving a rough idea how far ahead I can schedule my calender.

The best case scenario is an 80% chance of cure. If I live another five years the cancer is considered 100% cured. Which is my plan.

Nobody seems to be predicting the best case scenario, but everyone admits there is no way to predict what they will find or what will happen. The bottom line is the whole thing is a crap shoot.

Since no one knows what to expect, I'm betting on survival.

If the surgery goes well I will be starting the second round of chemo within two weeks after I return home. During the second round of chemo swallowing will be less of an issue because I will have a feeding tube. This is basically a tube coming out of my stomach where I will inject food directly into what's left of my digestive system.

This, combined with my chemo pump, will move me a step deeper into the Borg collective. Two tubes, instead of one, obviously places me closer to assimilation. I am already plotting my escape.

Picard takes a vacation.

August 11, 2010

Today I completed my first round of chemo.

Picard is taking a well deserved vacation from me, which he totally deserves. He will probably spend time on some tropical island, or perhaps just hang out in a drawer at Pacific Oncology, where he will enjoy some respite.

We are free from each other for at least six weeks. Free at last, free at last.

Free

AT LAST

My surgery has been scheduled for Thursday September 16th, so I have a little over a month to recover from round one of the chemo. I'm looking forward to resuming my swimming now that I no longer have to deal with Picard's fear of water.

On Monday August 16th I'll have another endoscopic ultrasound. That's where they cram a hose down my throat and take pictures of the tumor to see if it has shrunk. Since I get to sleep through the procedure it's not as nasty as it sounds.

On August 18th I go in for a CAT scan.

Dr. Ey wanted to do the more expensive, and more detailed, PET scan. However, the insurance wouldn't cover it.

We see this as a good sign.

If the PET scan had shown the cancer had spread the insurance company wouldn't have to pay for surgery. So this implies the insurance industry is so confident the cancer has not spread they'll risk not doing a scan that would have gotten them out of paying the surgery bill.

If they're that confident I'm in good shape, we're confident as well.

So once those tests are out of the way my schedule is free of medical stuff for three weeks. I intend spend the time immersed in a deep denial where I pretend life has returned to normal.

Because, in-spite of what you may have heard, denial can be a good thing.

Another endoscopic ultrasound test.

August 16, 2010

Today I went in for another endoscopic ultrasound test.

This is the test where they take a garden hose with a camera taped to the end of it and cram it down your throat.

And they say doctors don't have any fun.

Waiting for this test has been particularly nerve wracking since it's outcome was so significant. If the tumor shrunk, treatment progresses as planned. If the tumor had grown, it's time to consider the folks in the obituaries as my peer group.

The obituary crowd will have to wait, I'm not going to be hanging around with them any time soon.

The tumor had shrunk so much it wasn't visible, though they could still see the scar tissue where it had been. The doctor did a biopsy where the scar tissue was to determine if there were still any cancer cells left.

We will get the results of the biopsy in a few days.

The enlarged lymph nodes that they were previously concerned might be cancerous are no longer enlarged. The doctor did NOT do a biopsy on them because he no longer considered them potentially cancerous.

The fact of the matter is this is the best case scenario. Apparently this doesn't happen very often and is considered very good news.

They will want to proceed with the surgery because this will ensure the best chance of success. The bottom line is today's findings significantly increase the odds of a positive outcome.

So the next step is the CAT scan on Wednesday, which I'm not too concerned about. With the amount of toxic chemo chemicals they pumped into my system it's unlikely a few stray cancer cells survived the onslaught, much less spread.

So after that it's free time until the big surgery on September 16th.

Now that will be an entirely different story. But one I'm sure will be entertaining once I'm functional enough to tell it.

More good news!

August 18, 2010

We just got the results of the biopsy from the endoscopic ultrasound. The results were negative! There were no cancer cells!

I will still need the stomach surgery to remove any possible microscopic cancer cells, but the biopsy not finding any cancer is wonderful news.

It means the chemo worked even better than we thought.

The CAT scan results were fine.

August 26, 2010

The CAT scan results didn't turn up anything nasty.

We didn't think they would, but it's nice to have that confirmed. If I had it to do over I probably would have skipped this test. After the very positive results from the endoscopic ultrasound, a CAT scan seemed redundant and unnecessary.

Besides, the CAT scan is a yukky procedure. "Yukky" being a medical term you non-medical types probably aren't familiar with. It's not a good thing.

Actually, the test itself isn't so bad, it's the degrading way they treat you before the test that makes it unpleasant.

Though, truth be told, sitting in a room by myself in two hospital gowns (one forward, one backwards) watching children's television wasn't all that bad. I never did find out if the nerdy kid with the learning disability the other kids were picking on got his revenge. I suspect he did.

I hope so. I was rooting for him. I really wanted the arrogant evil teenager to get what he deserved. Not that I'll ever find out since I missed the end.

I've pretty much moved on. I'm swimming forty minutes a day and exercising to get as fit and healthy as I can before the surgery.

The residual effects of the chemo are wearing off and I'm feeling good. I should be in really good shape, by my standards anyway, by the time of the surgery.

I figure I'm going into surgery strong and healthy and have a good chance of breezing through it with minimal complications.

I hope, I hope, I hope.

Guest blogger.

August 26, 2010

Hi – this is Marcia, Gary's sister-in-law. While he is off having fun in the hospital in a few weeks, I have been asked to be a guest blogger – in other words to post to this blog to keep all of you updated on his progress.

Today's post is a test to see if I am technically capable of handling the task.

"You walk the walk and talk the talk. We need someone who can also blog the blog!"

If I pass, I will start the process of hiring a comedian to ghostwrite the posts so they can perhaps be as hilarious as Gary's. I hoping for one of the writers from The Big Bang Theory, but we will see.

If there is news to post while I'm at the hospital with Anne, we will flag down a southbound carrier pigeon and send word to my daughter and Gary's niece, Jennifer. She will then post the update, perhaps even from her iPhone.

Gary has been such a trooper through all this. I am optimistic that I will have good things to report.

Change in date and venue of surgery.

August 29, 2010

Dr. Tseng suggests we switch the surgery from St. Vincent to Good Samaritan Hospital and from Thursday September 16th to Monday September 20th. He gave two reasons.

He is more comfortable working with the staff at Good Samaritan because they are more familiar with how he works, which reduces the danger of removing the wrong organ. Actually, he didn't say the part about the wrong organ. I made that up.

Also he wanted the surgery rescheduled from Thursday to Monday so he could follow my progress for a week straight. This is a very good thing since problems that occur on weekends get routed to the on-call doctor, which is almost never a good thing.

This was all plausible, so we agreed to the change.

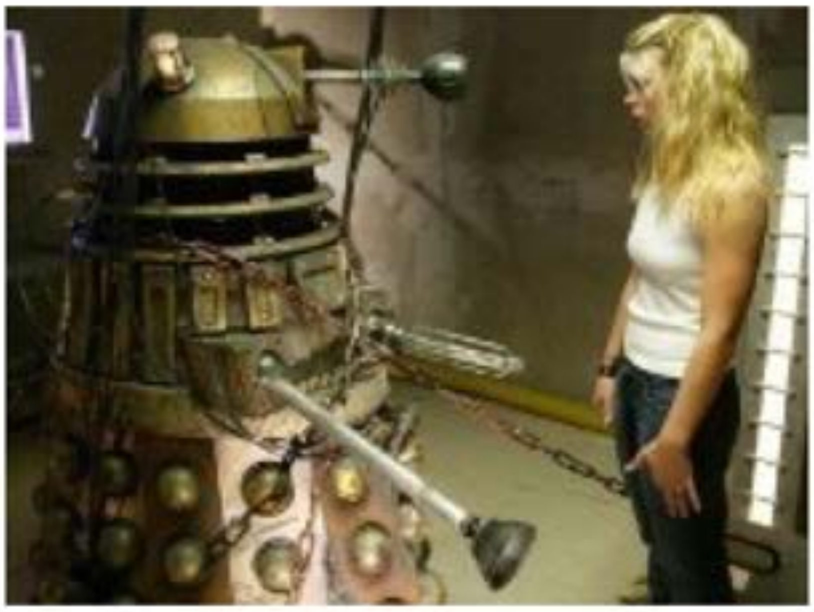
Truth-be-told, there is actually a better reason for the change.

The shopping is much better in NW Portland than in the gift shop at St. Vincents. Anne and Marcia can now hang out part of the time in trendy shops in NW Portland rather than being stuck in a hospital waiting room.

This will be a more pleasant way to spend their time while I'm off doing drugs in the operating room.

A visit with Dr. Tseng.
September 15, 2010

We met with Dr. Tseng today. This was a pre-surgery consultation prior to having him and his robot rebuild my guts on Monday.



We anticipated this might be one of those meetings where the doctor scares the bejeezus out of us by spelling out all the horrible things that can go wrong.

It wasn't like that at all.

Dr Tseng was extremely encouraged by the endoscopic ultasound results showing the chemo had caused the tumor to disappear. He was also excited the biopsy results showed no cancer.

His enthusiasm for my prospects for a total cure were tremendously encouraging.

He is the third doctor (Meyers, Shumacher, Tseng) who was visibly excited by the positive implications of the endoscopic ultasound and biopsy results. When all your doctors are excited by your prospects the excitement is contagious.

Dr. Tseng said these results significantly improve the prognosis for a successful outcome of cancer treatment. He also indicated my positive body habits would decrease the likelihood of problems in surgery.
"Positive body habits" is doctor speak" for "the guy's not too fat".

He's still going to remove the whole stomach. That's the only way to be certain the cancer is all gone. Plus I'm still going to have to do another nine weeks of chemo following the surgery.

Oh well. That's the way it goes.

But after that I’m done.

Living with a stomach built out of spare parts is going to be a challenge. I’ve known that all along.

What will serve as my stomach will be about the size of a small potato. Meals will be very small and very frequent. This will take some getting used to. Over time the new stomach will stretch. It might eventually end up holding as much as an old fashioned stomach, but only time will tell.

Another issue is my body may have problems handling sugar, which could mean drastically reducing the amount of sugar I can eat. This is a major disappointment. I love sweets.

But, hey, a frustrated sweet tooth is a small price to pay for not being dead.

The tiny stomach, and possible inability to eat sugar, will result in my being very thin. This means with a minimum of exercise I should end up with totally ripped abs. Which is something I’ve always dreamed of.

Consequently, my ripped abs will no doubt leave me the envy of the pot bellied men of the world. Or then again, considering the price I will pay for those abs, they might not envy me at all.

Surgery – Two days and counting.

September 18, 2010

On Monday September 20th I go into the hospital to have my stomach surgically removed and rebuilt. As you know, this is similar to having the engine in your car rebuilt, except the time in the shop is shorter.

The surgeon, Dr. Tseng, anticipates I will be in the hospital between five and seven days. If there are no complications I will return home and be able to pretty much resume my normal activities.

The only limitations will be that I will be tired a lot and will not be allowed to do things like sky dive, jump motorcycles over canyons, or bounce on trampolines. Another limitation will be that my stomach will be gone, but that just goes with the territory.

Surgery will last somewhere around six hours. We will be at the hospital by 5:15 AM and the surgery will begin at 6:30 AM.

The operating nurses will update Anne about my progress every couple of hours. Anne's sister Marcia and niece Jennifer will update this blog when there is anything significant to report. Personally, I'm going to kick back and catch a nap.

Following surgery I'll be moved to the ICU for a day or so. At that point I'll have quite a few tubes running out of various of orifices.

Some will be temporary orifices that have been custom built as part of this science project.

When it is decided to be appropriate some of the more annoying tubes will be removed and I’ll be moved to a regular room. At this point they will insist I get out of bed, move around, and take short walks down the hall. This is cool because I like taking walks.

The first few days promise to be fairly rocky, but it should get better soon. Towards the end of my hospital stay I should be feeling relatively good. In fact, towards the end the only reason I’ll be there is so they can keep an eye on me while I test drive my rebuilt stomach. If it has leaky valves or needs a new head gasket they want me close by so they can repair it before the warranty runs out.

When I leave the hospital I’ll be eating mushy foods for several weeks, then graduating to the hard stuff. From then on it’s a matter of practicing using my new stomach until I develop a feel for its strengths and limitations.

On Friday we met with Dr. Ey, the oncologist, and he became the fourth doctor to be exuberant about the results of the endoscopic ultrasound test. He made a rough estimate that only one in five people who go through my form of chemo have such positive results.

As soon as I adequately recover from the surgery we’ll schedule the next round of chemo. When that chemo will start is pretty much up to me, but I’m leaning towards starting it as soon as possible.

As entertaining as this experience has been, I’m ready to get in and get it over with. I’m ready to start thinking about things other than cancer.

6 - The Robot And After

Going Fine.
September 20, 2010

This is Gary's niece, Jennifer, posting. Here is an update I received from my Aunt Anne:

- Surgery began about 7am.
- Operating Room reported at 8:15am that things were going well.
- 13-year old Molly (dog) was hospitalized yesterday.
- Cats are a mess.
- Anne is hanging in there.

Your thoughts and prayers have meant so much to us all.

Out of surgery…

September 20, 2010

Gary is out of surgery and doing GREAT! Film at 11…

p.s. Molly is doing better too.

A job promotion.
September 21, 2010

Hi all, Marcia here with some additional details on the events of the day. Gary was in surgery about six and a half hours. Somewhere in that time a part of his small intestine was notified that, due to a job vacancy, he had been promoted to the position of Stomach. As we know, this title carries a certain amount of responsibility with it, so he's being given a few days to get used to his new coworker, Esophagus. Later in the week, they'll do a swallow test to make sure he is ready for the job.

When the doctor talked to us, all reports were good. He removed a lot of lymph nodes, but felt that none of them looked like they should be cause for worry. The pathology report will be back Wednesday or Thursday. There was no indication that the cancer had spread and when the margins going into the esophagus were checked, they were fine.

Gary will probably be out of ICU tomorrow. Until then they'll be watching over him closely just to make sure that nothing comes unstapled or otherwise goes awry. When Anne first went in to see him, when he came up from recovery, she said he looked good. He will probably not remember looking good.

Molly is also doing better. She's still in the hospital but her heart rate and fever are down. They'll know more about her specific condition in the next day or two. Anne is hanging in there, but needless to say, she has had a lot on her plate. They both appreciate all of your notes, thoughts, and prayers.

As more information is available, I'll post more. I'm sure you'll all be glad to have Gary's sense of humor back. For me, I'm just very, very happy that everything went so well today.

Update.
September 22, 2010

A quick update on Gary – He was kicked out of the ICU about noon today. Understandably, he's not feeling all that well. The nurse told him that this would be his worse day – possibly because they would be pushing him to do things he wasn't especially in the mood to do. Dr. Tseng is very happy with his progress. Anne continues to report that his color looks GOOD. I don't have the specifics as to what color that is. She was also happy that he was able to sit in a chair for about an hour and visit. He also talked about being hungry which is a sign that his digestive system is kicking in. That's GOOD too.

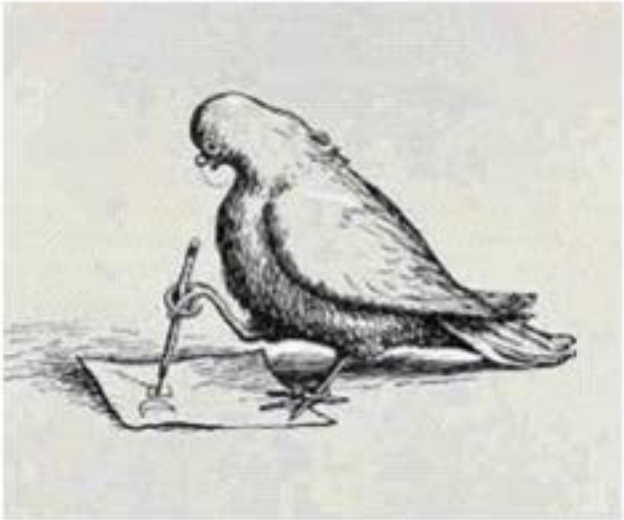
We all just want him to feel better soon.

Update day three.
September 23, 2010

It's another day of good news for the Olsons. Gary has walked down the hall and made at least one lap around the nurses' station area. This may or may not have something to do with the fact that he had a cute student nurse for a time today.

Although he's able to sit up with very little assistance (and then remain sitting on the side of the bed by himself), he is still on quite a bit of pain medication. This morning he told Anne, "I'm stoned". They have started or will soon be starting tube feeding into the small intestine and will include pain medication in the recipe. This will help keep his pain management on an even keel.

The swallow test is tomorrow. If that goes well, they'll start him on small amounts of liquids.



In other good news, Molly is home from the hospital. Despite the fact that she has a bad kidney infection (requiring six weeks of doggie antibiotics), she is doing very well and is back to her old self. The cats are happy but won't admit it.

Anne is very happy.

More news as it's available.

Update day four.

September 24, 2010

Things Gary has done today:

Passed the swallow test.

Had some of his tubes removed.

Walked numerous times (close to 20) around the nurses' station.

Got busted for not wearing nonskid socks on one of his walks.

Pleaded drug induced forgetfulness (re: the socks) rather than explain that the aid had forgotten to give them back to him after his shower.

Hallucinated/dreamed that this blog had been compromised and there were holly trees in the URL, which caused the internet to go to a holly farm. He apparently spent a fair amount of time trying to figure out how to fix this.

Got the good news from the doctor that things are going well and he should be able to go home this weekend.

Friday news.

September 25, 2010

One sip at a time…

Gary got to try out his new stomach today by sampling a number of clear liquids. There are still some hurtles to get over, but things are moving along. Hopefully he'll be able to come home on Sunday.

Anne and Gary appreciate all of your continued thoughts and prayers.

Pudding and ice cream.

September 26, 2010

Gary will be spending a little more time in the hospital. I personally believe it's because word of his sense of humor has spread and they are keeping him longer so everyone on the floor can experience it first hand. The "official" reason (translated from medical terms) is that something is still draining.

In eating news, his menu now includes not only liquids, but also very, very small amounts of soft foods – pudding, ice cream, etc. This is especially significant since those foods contain sugar and sugar can sometimes be a problem for people who've had this procedure.

Another day…

September 27, 2010

Lots of fine tuning for Gary today as they try to adjust his tube feeding and pain and anti-nausea meds. It was not his best day.

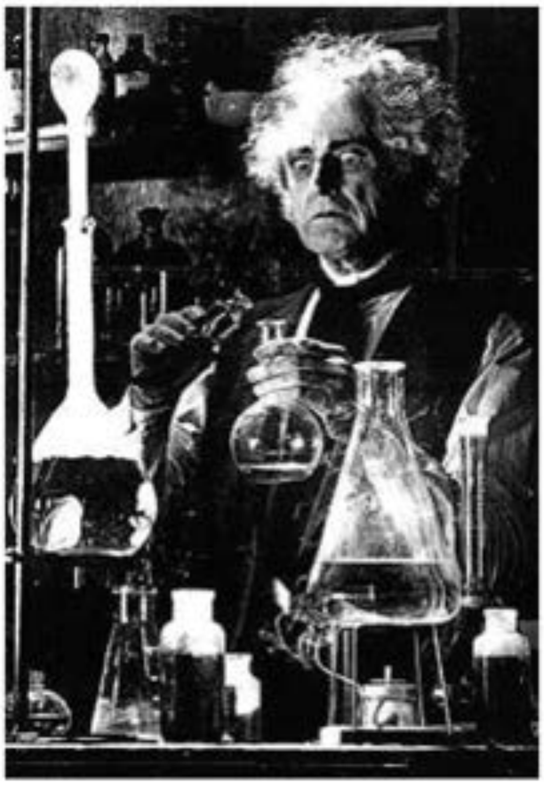
Please send him all your positive thoughts, prayers, and good energy.

A mad scientist and a descendant of Euell Gibbons.
September 28, 2010

Hello all – Marcia here with the latest news on Gary (via Anne). Although he still isn't having a lot of fun, he has, off and on, had times when he is feeling better today. He slept well last night and made several circuits around the nurses' station today.

Less positive is that he has something else going on – a side effect from the surgery.

So, for the time being, he has been taken off tube feeding and is getting his nutrition directly through his port. The formula, of course, is complicated and has to be created by a pharmacist working in conjunction with a nutritionist. Gary would have told you it was a mad scientist working with a descendant of Euell Gibbons.



Anyway, the concoction will have to be closely monitored and he won't be able to leave the hospital until everyone is sure that there is not too much of this or too little of that in the mixture. Once he's home, a home health nurse will be stopping by regularly to make sure that everything is going as it should.

This, of course, is an annoying detour he has to take before going back on tube feeding and taking longer test drives with his new stomach. It's always something, isn't it? We hope that all of this is behind Anne and him very soon.

Oh, one more thing. He asked Anne to bring his computer to the hospital. You have been warned.

Tuesday.
September 29, 2010

Marcia here again. Overall it was a better day for Gary. The new way of giving him his nutrition through his port is alleviating some of the problems he was having. If all goes as planned, he will be able to go home in a couple of days. There are still challenges in regards to pain and nausea management, and returning to tube feeding and then actual eating may be slow going, but he and Anne are taking one day at a time.

If it’s Wednesday…

September 30, 2010

If it’s Wednesday, things must be better.

Gary is feeling better and plans are that he will go home tomorrow.

They did a CAT Scan today to check for fluids, and although there were small amounts here and there, it was nothing to worry about.

The irony of it all of this is that they asked him (remember he’s the guy who has eaten next to nothing for a week and a half now) to drink a pint of liquid to prepare for the test. I can only imagine what I would have said as I think most of us, even at our best, would find CAT Scan Kool Aid less than appealing. The good news is that he got most of it down and followed it up with a chaser of a whole cup of milk. He tolerated both fairly well.

The pathology results were mostly positive. There was only one lymph node (out of the 26 they removed) that showed some cancer cells and there was only a tiny amount of cancer found at the tumor site. They’ll start him on the second round of chemo as soon as possible, and since we know that the last round did its job, everyone is optimistic.

Once home, Gary will continue receiving nutrition through his port. They will orchestrate this so that he only has to be “hooked up” during the night. The Borg analogy lives on. Dr. Tseng has also said that he can start experimenting with solid foods as long as he takes it slow.

One more day…

October 1, 2010

Marcia here again. Gary was not released from the hospital today, mostly because of administrative issues.

I suppose if one has to stay in the hospital an extra day, paperwork is the best of all possible reasons. One, for example, would not want the reason to be a sudden growth of blue hair all over one's body.

Likewise, one would not want to be asked to extend one's stay so one could wash dishes in order to cover a gap in the insurance coverage.

Anyway, in a nutshell, the resident who was supposed to give the written orders to the Mad Scientist so that he could make the concoction that Gary is receiving through his port and then send it home with Anne, Gary, and the Home Health nurse, didn't get out of surgery in time to make the cut off time for such orders. Now, everything has to wait until tomorrow.

Gary has also been dealing with a couple of other things today, so perhaps, in the end, it was good he stayed just a bit longer. We're just glad he'll be home soon!

7 - Home Again

Hooray!
October 2, 2010

Gary is home!

Sunday update.
October 4, 2010

Hi, Marcia here with an update on Gary. After a not so good day yesterday, he slept better last night and feels pretty good today. He is getting used to being hooked up to the TPN machine, which apparently makes Picard look like a pack of gum. Anne and he have successfully passed TPN training (provided by the Home Health Nurses) and are now allowed to play with the machine by themselves.

The very best news is that he ate small amounts of applesauce, cottage cheese, peaches, and ice cream today. Some of those foods fall into the category of “mechanical soft” which, until today, was a category that I never knew existed. He is now craving chicken noodle soup.

Home at last. If I only functioned well enough to appreciate it.

October 4, 2010

As you know, I’m back from the hospital. I’m not functioning at my usual 100%, more like 1.2%.

That’s a rough calculation, so don’t use it for analysis of my professional abilities. Truth be told, I can barely make this keyboard operate.

You wouldn’t believe how many problems I had getting the picture below taken, edited, and posted. But a picture is worth a 1000 words, and this picture says it all.

I am a zombie.

I’d like to thank everyone who has stood by me during the difficult hospital experience. Your thoughts, prayers, and warm wishes have been tremendously important.

And, of course, I want the offer a special thanks to Anne's sister Marcia, my blog co-host.

I’m sure you’ll be hearing more from both of us.

One peach slice at a time…

October 6, 2010

Hi, Marcia here with a quick update on the Olsons.

It seems that every day is a little better. Complications today were mechanical rather than medical and related to pumps that wouldn't prime. They can put a man on the moon, give a guy a new stomach, but…

Gary is continuing to experiment with eating and had one more peach slice today than yesterday.

He's still receiving most of his nutritional needs via his port, but once his chyle leak (you'll have to Google it) is healed, he will progress to tube feeding.

He was also able to walk down their side street to the next street and back. He has progressed from just plain feeling crappy to "recovering from surgery".

Anne had a day free from health related phone calls, Home Health nurse visits, etc. and was even able to get her bangs trimmed. Hooray for a little normalcy!

An eyewitness report…

October 8, 2010

Hi all, Marcia here with an eyewitness report on all things Olson.

I saw Gary today and you know, he looks darn good. I've seen people look worse after a particularly difficult Western Civ final and a bit too much Annie Green Springs. The guy deserves a medal. He was telling me how he has been "training" for this (meaning the chemo, surgery, and another round of chemo). I loved the term "training". He's diligently doing everything he's been told to (and a whole lot more) in order to beat this thing. We would have talked longer, but he was headed out for a walk.

Speaking of medals, Anne deserves one too. She is excelling as Mad Scientist's assistant. If you ever want someone to meticulously add the perfect amount of insulin and vitamins to your nutrition cocktail, she's the one for you.

A day in the life.

October 10, 2010

For those of you who are curious about my post surgery life I wrote this post. If you're looking for something light and funny, you might want to skip this one.

For starters you need to understand that I returned from the hospital with more parts than I had when I went there. I now have a feeding tube, a drainage tube, and a machine that pumps nutrients directly into the port to which Picard was attached. All of this requires care and attention.

I start my day between 7 and 8 AM, whenever I wake up. Some nights are better than others, but getting a good night's sleep with the tubes and machine attached is challenging.

I get up and read the paper with Anne. We visit awhile but I soon get tired so I go back to bed and finish off the poor night's sleep I got. After this final round of sleep I'm good to go.

Meanwhile, Anne has given Molly a couple of different sets of meds and coaxed her to eat whatever she can. Molly is doing much better than when we almost lost her when she was hospitalized during my surgery but still has some kidney issues. It has taken a lot to get her back to eating somewhat normally.

When I get up I begin taking my Chinese medicines which I do throughout the day. My body is totally out of sync and early morning is often challenging. I take everything very slow.

A problem I've been experiencing is my metabolism is out of whack and I am extremely COLD. I'll wear two T-shirts, a lined shirt, a heavy sweater, park myself in front of a space heater, and I'm still cold. At the same time, Anne will be about to pass out from the heat. Fortunately, this situation appears to be correcting itself.

During the morning I am lugging around a feeding machine that is housed in a green backpack. I've been attached to this gizmo since 6 PM the previous evening.

Around 10 AM the machine beeps at me to say "You're fed. You can unplug me now". This begins one of the busiest times of the day. We open up the back pack and shut down the feeding machine's computer. Then Anne detaches me from the machine, flushes my PowerPort with a hypodermic syringe, and I am free for a few hours!

The next step is to maintain my tubes. To protect those of you who are squeamish, we won't go into any detail here!

I then take a shower which is more challenging than it sounds.

Next, Anne changes the dressings on my tubes. The changing of the dressings is a complex ritual that is one of the more unpleasant aspects of this whole regime, mostly because it hurts when Anne pulls up the tape. It was even more painful when the nurses did it, so I have no complaints.

We then have a little lunch. One of the nice things is that we are now able to eat this meal together. Sometimes, we even eat the same thing.

I am working in increasing my ability to eat solid food. Right now, I can only eat small amounts of soft foods with negligible fat (the latter has to do with the chyle leak). I have successfully eaten chicken noodle soup, mixed canned fruit, apple sauce, and peaches. Tomato soup and bread with jelly didn't go so well.

After lunch, we often have an appointment with my Chinese medicine doctor/acupuncturist or the home health nurse comes by. If not, Anne tries to run a few errands like going grocery shopping. Lately, we have actually managed to eke out a couple of free hours in the afternoon. Yesterday, we actually watched a movie.

I am trying to spend more time walking since exercise improves the recovery time from surgery. This is challenging since I have little stamina or endurance. I am trying to walk around the block at least three times per day. I move very, very slowly, but at least I am moving. Which is what counts.

Around 4 PM Anne begins to prepare the formula for the machine that feeds me. She removes a feeding bag the size of a hot water bottle from the refrigerator and inserts special nutrients and insulin into the bag using a hypodermic syringe. She then hooks it to the pump, powers it up, and puts the whole thing in my special back pack. It is quite the project.

I eat another little meal around 5 PM and then accompany Anne and Molly on the first part of their walk.

Around six PM, Anne reattaches me to the feeding bag which is quite the little science project in itself. Anne then gives Molly some more meds and fixes a little dinner for herself.

I'm very tired in the evening and mostly just sit in my chair. Last night, I was actually able to talk to Anne.

Since sleeping is such a challenge, around eight PM I take some Tylenol and a very hot soak. This makes it easier to sleep, which is something I desperately need by this point. While I'm soaking, Anne coaxes Molly to eat some more.

I'm in bed before 9 PM, and I think Anne goes to bed soon after.

And that's it. A typical day. It is definitely a “one day at a time” kind of experience with each day being a little better than the last.

Not much better, but better.

Thanks again for all of your emails, blog comments, cards, and silent prayers. A very special thanks for the vacuuming, the purple dahlias, the pharmacy run, the chicken Parmesan and stuffed zucchini, and the pumpkins on the porch! You know who you are!

Tuesday Update.

October 13, 2010

Hi, Marcia here, guest blogging for Gary. Here's a bit of an update on the situation.

It's unfortunate that Gary's new stomach did not come with an owner's manual, as eating is a bit more challenging for him this week than it was last. This, of course, is frustrating, especially since there doesn't seem to be much rhyme nor reason as to which foods work and which foods don't. For example, things he tolerated well last week have given him trouble this week.

They met with Dr. Tseng today and everyone agreed that the second round of chemo should be postponed until Gary is feeling better. No one seems to be concerned that waiting will be a problem.

He will soon be off the TPN and graduate to tube feeding. It will be a new routine and process to get used to, but hopefully he won't feel so cold all that time when chilled substances aren't being pumped into his body.

It goes without saying that this is no fun for either Gary or Anne. We know things will get better, but for now, your continued thoughts, prayers, and positive energy are appreciated. They have both been so touched by everyone's kind words and deeds.

Batteries not included.

October 14, 2010

So, you know how when you were a kid and you got a really, really cool toy for Christmas, and you were so excited, and then you discovered that the batteries were not included, and since it was Christmas all the stores were closed, so you were going to have to WAIT to play with it? Well, in my analogy challenged mind, that's about what happened to Anne and Gary today.

Gary slept well last night and felt pretty good this morning, and so the day started out on a positive note. Then, because my sister is a genius (not to mention tenacious) she was able to figure out, through creative sleuthing and Googling, why foods weren't agreeing with Gary this week. The problem had an easy solution and he not only had a good lunch (with no adverse reactions), but also ate a "meal" at 2:00 pm.

Unfortunately, a phone call from the doctor's office brought everything to a grinding halt. It seems that he has both an infection and a leak. Neither of those things are on most people's Christmas lists. The infection means two weeks of a couple of kinds of antibiotics. The leak, although small, means no more food until it has healed. It looks like Gary will have to wait to play with his new stomach.

This also means that he will likely have to go back on the TPN nutrition, rather than staying on the tube feeding which he switched over to today.

Needless to say, this is quite frustrating. The proverbial one step forward and two steps back somewhat overshadows the really good news of the day.

Thanks to all of you who either faithfully or intermittently read this blog. Your comments mean so much to both Gary and Anne.

This is not it…

October 18, 2010

Hi, Marcia here with an update.

In Gary and Anne’s world of recovery from surgery, medical devices, complicated tube feeding, antibiotics, and crummy side effects, suffice to say that they’ve had fun before, and this is not it.

Please keep them in your thoughts and prayers.

Things go better with Coke.
October 20, 2010

Hi, Marcia here with an update.

Gary and Anne started their day with a plugged feeding tube. They were told by one medical professional that a mixture of baking soda, meat tenderizer, and water was what was suggested in the past to unplug it. I always thought that that was what you put on bee stings, which shows how woefully under-informed I am. This concoction, however, is apparently no longer recommended for plugged tubing. The next health care provider asked Anne if she'd tried Coke. There was no mention of Pepsi or RC.

Anyway, as it turned out, it was a non-issue for now. After seeing Gary today, Dr. Tseng wants him back on the TPN feeding. The tube will remain plugged until such time as it is needed again. It will then first be cleaned out by a radiologist (most likely with a minor in plumbing).

After all is said and done, nearly all the news today was good.

Gary's white blood cell count is back to normal which means the infection is under control or gone. He will continue on antibiotics for two more weeks, but they switched him to one in a liquid form so he won't have to deal with swallowing pills. This was causing him a great deal of trouble.

Although Gary's leak has not completely healed yet (and possibly has gotten larger due to the vomiting and gagging that he has had to put up with) the CAT scan he had today (another adventure in and of itself) revealed nothing to be concerned about and no other problem areas.

The area around his tubes looks good.

Dr. Tseng feels that Gary is doing fine and the things going on are “normal” – not necessarily fun, but normal.
Of course, we just want Gary to FEEL BETTER QUICKLY. What a trooper he has been.

I know that many of you check this blog daily and worry when there is no new post. Sometimes there is just nothing to report – things are basically the same. However, please know that if something significant happens I will post it as soon as I possibly again.

Otherwise, I’ll try to post something every couple of days, or daily if there is even the slightest bit of news. Knowing that you are out there reading means the world to them both.

Would you like sauce with your rigmarole?

October 20, 2010

Hi, Marcia here again with an update.

Anne reports that Gary felt pretty good last night. They are getting used to the new routine of administering the antibiotics with a gravity drip (bag hung from pole) through his port for 30 minutes before starting his TPN.

When they left the doctor's office they were under the impression that the liquid would be added to the TPN. One has to be rather flexible and resilient if one is going to go through something like this.

In additional to the physical difficulties that Gary is putting up with, the Olsons seem to be dealing, on nearly a daily basis, with a certain amount of rigmarole. Coordination between doctors, medical professionals, Home Healthcare, advice nurses, dieticians, and agencies of one kind or another often requires multiple phone calls.

Even the task up obtaining extra sponges for Gary's drain became complicated. Who exactly is supposed to provide those? What if you need more than the 67.375 that each patient is statistically predetermined to require? And, when does it cease to be frustrating and begin to be almost, but not quite, laughable?

Thursday update.
October 21, 2010

Hi, Marcia here with a quick update.

Although tired, Gary had a good day yesterday – lots of sleep the night before, energy for two walks (he'd only been doing one for the past several days) and, since is GI system is taking a break, no yucky side effects.

The one mishap was when they tried to use a little of the antibiotics to clean the floor.

Saturday update.

October 23, 2010

Hi, Marcia here with a Saturday update.

I saw Gary (and Anne and Molly) yesterday. Gary's color is better than the last time I saw him. For English majors like myself, that's the scientific way of determining how someone is doing.

Anne's email this morning had this to report…

Gary continues to sleep long hours but feel rested when he gets up. He finally started reading again! And he has started to make a few of those Swedish humor type comments. Those with doing extremely little things around the house all show me he is more himself.

We are hopefully optimistic that each day will continue to find Gary feeling better.

Thanks again for all of your support.

Using toenails to measure progress.

October 25, 2010

I measure my progress by the number of little tasks I am able to do that I previously found overwhelming. I've been meaning to trim my toe nails for the past three weeks, but it was more that I could handle.

Today I trimmed them. A small victory, but a sign things are getting better.

Things have improved considerably since I started getting fed through my vein rather than the feeding tube. Being on the IV antibiotic is also a huge improvement over the pill form. Talk about gag me with a spoon, those pills were awful.

It's interesting not eating. I'm always a tiny bit hungry, but not unpleasantly so. However I am consumed with fantasies about food, most of which include a lot of red meat. This is strange since I seldom eat meat.

Our friends and relatives have supplied Anne with a wonderful supply of meals. Each night I have her give me a detailed description of what culinary delight she is experiencing.

I then retreat into my fantasy world of greasy spoon hamburgers, homemade hamburger intense chili, hot dogs, Hawaiian pizza, and, of course, my favorite, a whole box of Kraft Macaroni and Cheese saturated with Heinz catsup.

An unanticipated aftermath of the surgery is the healing process has sucked the blood from my brain. I have found it difficult to read since concentrating is so difficult. This was quite a lifestyle change for a guy who usually reads four or five books at once.

I am reading again. I am even reading a book that is considered a classic of American literature. Of course what makes it literature is the author spends four paragraphs describing the autumn leaves blowing across the court yard. I skim that part and jump back to the plot, which is quite interesting.

I’m now walking about eight blocks twice a day. I’d walk more but getting my nutrition through a tube hasn’t been quite enough to match calories burned. I’ve already lost over ten pounds and I don’t want to burn off too many calories.

I’d like to thank everyone who has come to visit me. It’s nice to have company even though I don’t always have the energy to be a sparkling conversationalist. Oh wait, I was never a sparkling conversationalist. I guess that isn’t a problem after all.

I follow all of your blog comments and appreciate them greatly. I haven’t responded to them as well as I might have because my brain has been in a such a muddy swamp. Sometimes I don’t have the mental energy to do even the simplest tasks.

But today things are better, so I figured I’d write this post as a way of dropping by to say “Hi”.

“Hi”.

Another visit with Dr. Tseng.

October 27, 2010

Hi, Marcia here with an update on Gary and Anne's visit with Dr. Tseng. Please don't worry that it is me, not Gary, doing the posting. We're taking turns.

Dr. Tseng was reassuring – a good quality in a physician. He said that Gary is basically in a holding pattern while his leak heals and that sometimes takes time. Gary's leak, mind you, is really not all that impressive – rather lackluster in fact. Apparently it is only about a 1% leak, but it is a leak nonetheless. Gary will continue on antibiotics as a precautionary measure.

They will see Dr. Tseng again in two weeks and Gary may be ready for another swallow test. When he passes that and everyone is sure that everything else is where it needs to be, he will start experimenting with eating again. If all goes well with eating, perhaps two or three (or more) weeks later he will start his second round of chemo.

In the meantime, he says that he feels better today than yesterday. Anne reports that he walked further today than in days past, he's been doing a couple of chores around the house, and his cheeks look downright rosy. He is even talking a bit about driving soon.

Molly continues to be Anne's second patient. Anne spends a fair amount of time looking for the perfect diet for a dog with some kidney issues and one that that dog will eat. Molly recently dined on a hamburger couscous meatloaf. I think there might have been parsley on the plate. Lucky, lucky dog.

Delivered in 30 minutes or it's free.

October 29, 2010

Delivered in 30 minutes or it's free – oh wait, that's pizza.

Marcia here with an update.

Gary and Anne's latest adventure started yesterday when his TPN was not delivered by 5:00 as it was scheduled to be. The Olsons finally had to go and pick it up themselves at a warehouse at 10:30 pm. This meant Gary started receiving his nutrition five hours later than he was supposed to and had less of a night's sleep than he really needed. That, and an adjustment in the insulin he's receiving, pretty much wore him out.

I wish I could stop there and say that that was the only complication they have experienced. Unfortunately, it's not. Gary's drain tube came out today. This happened because the sutures holding it in had come undone some time ago – a fact missed or considered not to be a problem by more than one member of the medical community.

So, Gary had another appointment with Dr. Tseng today. Not having a drain tube is cause for concern because of the leak. The leak can allow substances to go into the body and that in turn can lead to an abscess or more serious infection. Not having a drain tube can also be a blessing in disguise, as sometimes that enables the body to heal more quickly.

The next few days will be important. Best case scenario is that the leak will heal and that will pretty much be it. Even though the tube is missing, there is still a "channel" of sorts there which may allow any fluid that is gathering a way out.

Other scenarios are not so positive and could include a trip to the ER resulting in anything from having a stint put it, to a round of heavy duty antibiotics (with a stay in the hospital), to actually requiring surgery. And, unfortunately, as Dr. Tseng is leaving on vacation on Sunday, this surgery would almost certainly not be done laproscopically.

Basically, I want you to ignore the last paragraph and hope, pray, and believe that none of those things are going to happen. Please send all of your healing thoughts and prayers to Gary (and Anne) as they face this newest challenge.

Saturday update.

October 30, 2010

Hi, Marcia here with a quick update.

There have been some encouraging signs at the site where the drain tube was, but we are still holding our collective breath. Apparently tomorrow or any of the few days following is the likely timeframe that signs of an infection would start showing up (if indeed an infection develops at all).

I can think of several thousand other things it would be more fun to be waiting to see if are going to happen.

Not Borg material.

November 2, 2010

Although we are not quite ready to breathe a collective sigh of relief, we have let out just a bit of the collective breath we've been holding. The weekend passed and Gary didn't end up in the ER with an infection.

We are waiting for the next few days to pass and along with it the danger of an infection. Thanks for all the prayers and positive thoughts and energy. We know it has helped.

In other news, Gary felt well enough to attend the Washington County Public Affairs Forum today. I'm sure they were very happy to have him back. He actually feels better without the tube in his body. He was never really cut out to be a Borg.

Another day…

November 4, 2010

Hi, Marcia here with a quick update.

Another day, still no signs of an infection. We’re liking this.

Was it the dancing cows?

November 6, 2010

Hi, Marcia here with an update.

I saw the Olsons yesterday. Gary seems to have avoided the infection Dr. Tseng was so very worried he would get. KNOCK ON WOOD. Was it the antibiotics he is on? Was it because his leak finally healed? Was it just luck? Was it his Facebook post about dancing cows?

Whatever the reason, we're sure that your thoughts, prayers, and positive energy were a part of it. A million thank you's.

Dr. Tseng is more than happy.

November 10, 2010

Marcia here with a quick update.

Gary and Anne saw Dr. Tseng today and he was more than happy that Gary was not in the hospital. When he arrived home from his vacation on Sunday (at midnight), the first thing he did was check the hospital list to see if Gary was on it.

Next:

Gary has another swallow test on Thursday. This is to confirm that he is ready to start “eating” again. Everyone agrees that it is important to take it slow and Dr. Tseng wants him to start with only liquids. They’ll see him again next Tuesday.

No leak.

November 13, 2010

Hi, Marcia here with an update.

I saw the Olsons today. Gary couldn't visit for very long because he was off to take his swallow test. He is such a gadabout. The test had been postponed from yesterday so he had an extra day to study. It must have worked because he passed! Yea! No leak! That means he can soon start his liquid diet. We're keeping our fingers crossed that eating/drinking will not cause him any problems.

I'm sure that there's a good plumber joke/cartoon to go along with this post…

8 - Real Food

Hamburgers, Hawaiian Pizza, and Meaty Chili.

November 13, 2010

I have become obsessed with food.

Not to complain, but I haven’t had a substantial meal in two months. For the most part I’ve been fed through a little tube, which isn’t as bad as it sounds. But I don’t recommend it.

Getting fed through a tube that shoots nutrients directly into my artery (or is that a vein?) keeps me from getting light headed or wobbly. But it never entirely gets rid of the hunger.

I’m not starved, mind you. I just always feel like hollering “Is it time for dinner yet? Shall I slap a 26oz steak on the grill?”. Of course the answer I come up with is always “We don’t have a grill and you don’t have a stomach.”.

Drat.

So I turn to fantasy.

I started with fantasies of thick juicy hamburgers, hot dogs smothered in catsup, meaty chili, and Hawaiian Pizzas.

All of which are very high fat foods which I don’t normally eat.

Obviously my body is craving fat.

Anne and I will go for a drive and she’ll say “Look at the beautiful fall foliage.”. I’ll say “Hey look, there’s a Burgerville and a Pizza Hut right next to it.”. Beauty truly is in the eye of the beholder.Now I’ve moved on to fantasizing about cooking Thai food.

I’ve been scouring the internet for my favorite Thai dishes. I’ve studied the ingredients. I’ve ascertained I can get everything I need from local Asian markets. I’ve ordered a bunch of Thai cookbooks through the library.

I am ready to go.

The only question remaining is whether I’ll still be interested once the hunger pangs subside?

Ice cream is exquisite. What a pity it isn't illegal. ~Voltaire
November 17, 2010

Hi, Marcia here with the Tuesday update.

The Olson's saw Dr. Tseng today. They decided that Gary would stay on TPN feeding and work towards the goal of him getting all of his nutrition from food he actually eats. This means he will skip returning to tube feeding which neither Gary nor Anne are sad about.

They'll start by reducing the calories in the TPN so Gary will be more "motivated" to eat on his own. They'll continue to reduce the number of calories with the hope of having him completely off the TPN in a couple of weeks.

In the meantime, he has really been enjoying his ice cream and is feeling much more energetic than he has been – possibly because he's off the antibiotics now or possibly because he gets to eat ice cream.

Breaking in the new stomach.

November 19, 2010

No hamburgers, Hawaiian pizza, meaty chili, or macaroni and cheese drenched in catsup allowed. Only soft foods.

Butterscotch pudding is soft, so I made some. (See picture) Made it from scratch. Added extra butter.

It is so good.

Now that I'm no longer leaking I've moved on to breaking in the new stomach. This has not been particularly pleasant, other than the butterscotch pudding part. Which was very pleasant.

I am eating six times a day. The portions are about one half a cup each, which isn't very much. About fifteen minutes after I eat my stomach sends a message whether it approves of what I ate.

Thumbs up. Thumbs down.

When it's thumbs down it can be fairly nasty. Sometimes the discomfort can be alleviated with a good belch. Sometimes it takes more. Sometimes I just have to tough it out.

This makes eating similar to playing Russian Roulette. I never know when I'm going to bite the gastric bullet. I just pull the trigger and hope for the best.

I have a theory. Only my brain, not my body, was consulted about loosing the stomach. Consequently my body is pissed off.

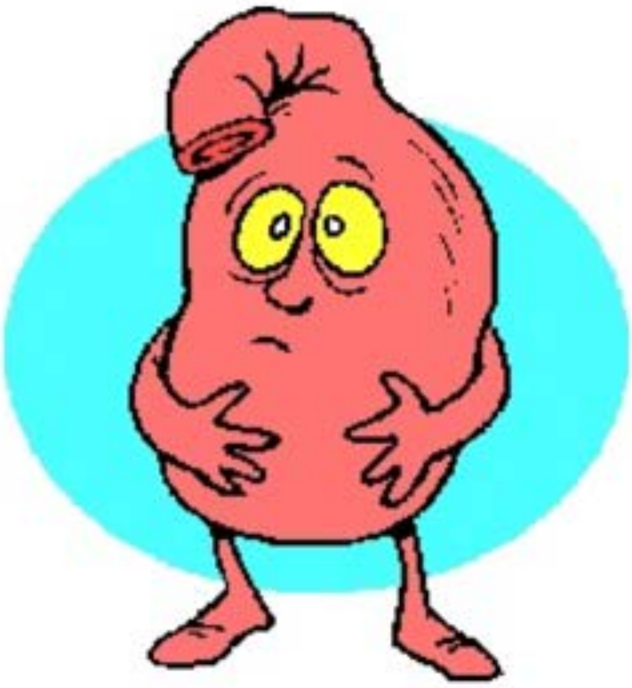
It is out for revenge.

I’ve apologized, repeatedly, but it’s not buying it. Over time we will make up, but for the moment our relationship is tense.

Has my stomach forgiven me?
November 23, 2010

As I speculated in my last post, I think my intestines have been giving me so much distress because they are pissed off I didn't consult with them before having my stomach surgically removed.

This is entirely understandable, though I doubt they would have been any kinder if they had been consulted. They probably would have yelled "surgery! Absolutely not! We forbid it!", and been just as pissy because their demands were not met.



None-the-less, things appear to be looking up. My stomach appears to be forgiving me.

Over the past few days putting food in my stomach hasn't resulted in any major gastric rebellions.

Oh sure, I'm still a little queasy at times. But over all eating is going much better. Not only is there less distress, but I am able to eat more food. This is significant because the more food I can take in by mouth the sooner I can stop getting my nutrition through a tube.

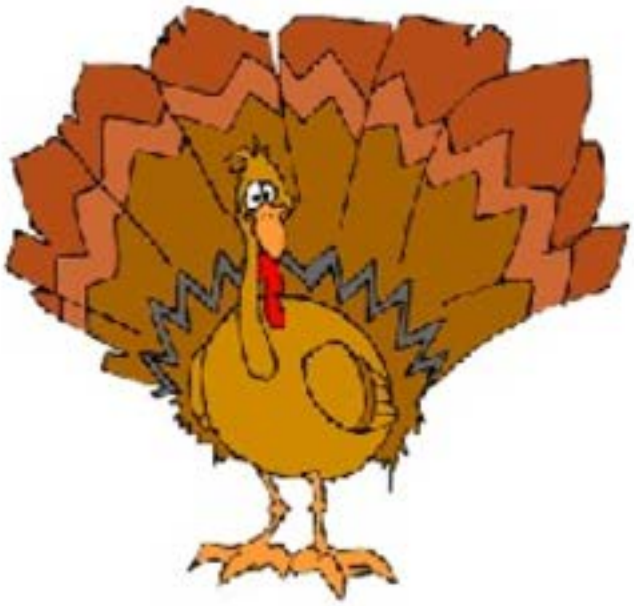
And I am so ready to be rid of the TPN tube.

Turkey.

November 24, 2010

I can eat turkey!

I have to cut it into itty bitty bites, chew it until my jaws cramp, but I can eat turkey.



We visited with Dr. Tseng yesterday. He said he thought it was time I graduated to more solid foods.

This means I can have a Thanksgiving dinner. Of course, with a stomach the size of a medium potato it will be a very small Thanksgiving dinner. But it will be a Thanksgiving dinner none-the-less.

Obviously, this is a huge step forward.

What is left on my “do not eat” list are foods that are hard to digest (steak), foods that have sharp edges (popcorn, hard bread crusts), and spicy foods. There are other foods I need to be careful about, but those are the main ones to avoid.

Last night I had some of Marcia’s Tuna Noodle Casserole. Boy was that good. It’s been months since I ate anything that actually had flavor. It was wonderful.

The other thing Dr. Tseng did was order the calories in the TPN to be reduced from 2000 a day to 1000. This means I will increasingly be getting my nutrition the traditional way rather than through a TPN tube.

I could be off TPN in a few weeks.

Yeah.

More Good News.

November 30, 2010

We visited with Dr. Tseng today. It went well.

To bring you up to speed, I enjoyed a great Thanksgiving dinner where I ate a little bit of everything and seconds of some things.

Unfortunately, my GI tract rebelled over the weekend, making things fairly unpleasant. Fortunately, by Monday it was behaving itself and I feel better than ever.

Dr. Tseng explained that when you don't use your intestines for two months they forget what their job is. When you remind them by passing food to them, they act out. It's childish and annoying, but you have to work with them until they are ready to behave.

My new stomach appears to be ready to start behaving. Last night I had a baked potato with lots of toppings for dinner that was the size I used to eat with my old stomach. It never occurred to me I might finish it, but I did.

And my stomach didn't rebel. Which is very encouraging.

Dr. Tseng is very pleased with my progress.

He is quite impressed with how little weight I have lost. He is pleased in particular with my little tummy roll. Personally, I was hoping the tummy role would go away, but I guess you take your good news in whatever form it presents itself.

I've asked to be on the 1000-calorie TPN for another week. This should give me time to build up to the 2500 calories a day I need to maintain weight without it.

After that, if all goes well, I’ll be off TPN forever.

I asked Dr. Tseng if the fact the first round of chemo was so successful indicated my odds of surviving long term were improved. He indicated this was true. People who respond well to the chemo are much more likely to have a positive long term prognosis.

I thought this was true, but this was the first time I had it confirmed. Obviously it make me feel really good.

It looks like I won’t be seeing Dr. Tseng on a regular basis anymore since the surgery phase of this process is complete.

Now it is on to the final round of chemo.

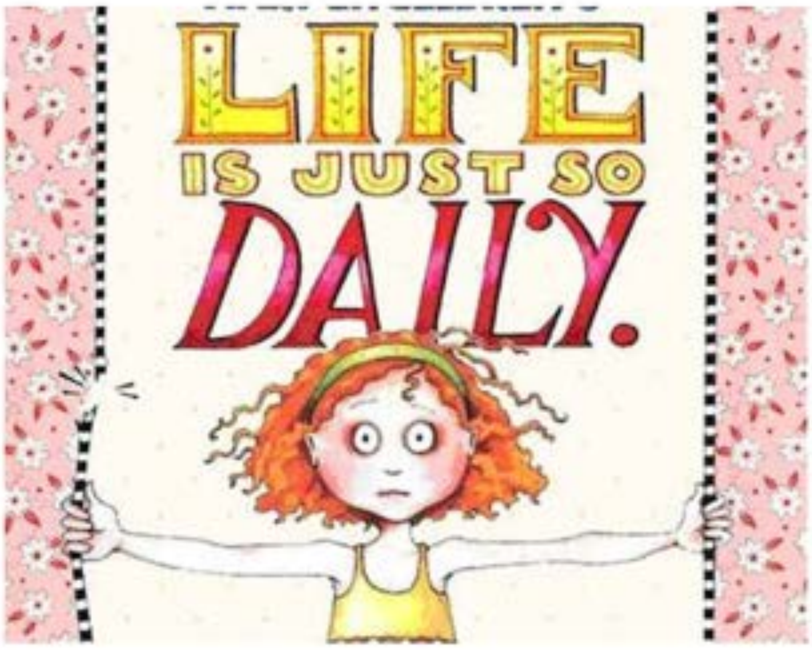
It is scheduled to begin on December 15th. Wish me well.

Life is just so daily…

December 5, 2010

Hi, Marcia here with an update on the Olsons.

Those of you who are Mary Engelbreit fans may recognize this image. It is one she has used on several of her calendars. It also seems a perfect description of the Olson's life right now. Although things are headed in the right direction for Gary, the day to day realty of his treatment and recovery is often quite wearing – for both Gary and Anne.



He continues to add new foods to his diet – that's a good thing. However, he has mixed success with how he feels afterward, and a lot of days he just doesn't feel that good – queasy, low energy, etc. That gets old.

On Monday, they are going to ask Dr. Tseng to take him off TPN. Hopefully, he will be able to get sufficient caloric intake only from the food he eats. As a backup, they will request that his tube for tube feeding be "reactivated". There are some problems with it now and it is only serving decorative purposes.

So, collectively, let's hope/pray that the next several days go well – that taking Gary off TPN helps make him feel better, that he is able to (comfortably) eat sufficient amounts to avoid any supplemental type of feeding, and that he will be in good shape to start chemo as soon as possible.

Free at last.

December 8, 2010

Hi all, Marcia here with an update.

After two months of needing to be hooked up to bags, bottles, tubes, and any number of other devices, Gary is officially unhooked. No more TPN.

This means he is on his own when it comes to meeting his nutritional needs. Tube feeding is still available as a backup, but it would require replacing his tube as the "wire thing" (obviously a highly sophisticated medical device) needed to repair his existing one was not available when they visited Dr. Tseng's office today.

All of this means that Gary is one step closer to starting chemo again. He starts next Wednesday. Between now and then he will concentrate on eating as much as his appetite and stomach will allow, and on maintaining, if not increasing, his weight. Go Gary go!

Lose 30 pounds in 30 days.

December 11, 2010

I always scoffed at those signs posted on telephone poles reading “Lose 30 pounds in 30 days”, but that’s exactly what I am doing.

Since I’ve gone off TPN I’ve been losing about a pound a day. This isn’t necessarily a good thing, but we’re figuring it’s all part of my body finding equilibrium. Pretty soon my weight should stabilize.

The good news is I can eat anything I want, am not hungry all the time, and am not short of energy from too few calories. So far the only foods I can’t eat are toast, shitaki mushrooms, and honey. I also can’t eat pills in capsule form.

I’ve successfully eaten pizza, baked potatoes, hearty soups, and scrabbled eggs. If fact, I’ve eaten most of the foods I was fantasizing about when I wasn’t allowed to eat. Fulfilling those fantasies has been delightful.

Of course my stomach hasn’t totally adjusted, so digestion offers some challenges. But overall things are moving along nicely.

Another encouraging thing is my hair is growing back. As often happens with chemo, my hair is growing back much curlier than before. I’ve let it go natural by not combing it. It looks really good. It could look less good if it grew longer, but that won’t be a problem since I start chemo on Wednesday.

So the take home message is I’ve found a “Lose 30 pounds in 30 days” diet program that works. Not only that, but the program curls your hair at the same time. How cool is that?

The only down side is it is a program I wouldn’t wish on my worst enemy.

9 - Just Grit

Last term at CU.
December 14, 2010

Hi all, Marcia here.

As most of you know, Gary starts the last phase of his treatment tomorrow. It's kind of like starting your last term of college. You're almost through, but you still have to endure nine weeks of some dreadful class – in his case one taught by Professor Chemo and his annoying TA, Picard.

So, I hope you'll all join me in sending Gary your positive thoughts and prayers. Thursday through Sunday may be difficult for him. He will have just received a mega dose from the professor and no doubt be wishing that he'd signed up for basket weaving instead.

Stepping off a cliff.

December 15, 2010

Hi, Marcia here with an update.

Starting chemo again must be like jumping off a cliff because you know there's something good at the bottom. It's that first step that's the hardest. Gary did, however, take it today and is now hours closer to being done with all of this stuff. It truly is one step at a time.

Dr. Ey was concerned about his weight loss (he's down six pounds) and, as a result, it looks like he'll start back on tube feeding next week. We're all bummed, but hey, if you're going to become a Borg, you might as well go at it whole heartedly.

News past and present.

December 19, 2010

Hi, Marcia (Anne's sister) here. Those of you coming to this site for the first time likely arrived via a link in Anne and Gary's Christmas Greeting. For you, here is the Reader's Digest version of the events of the last several months.

Last spring, Gary was diagnosed with stomach cancer. As he learned more about this disease and his treatment plan, he started this blog…

a) to keep friends and family informed

b) as a means to process through this significant challenge in his life and

c) as an excuse to use his "unique" sense of humor

When he has not felt like updating it, I have filled in.

Gary's treatment began with nine weeks of chemotherapy. This included carrying around a device he named Picard (after a contest on this site) which administered the chemo 24/7 and an additional three mega doses he received three weeks apart. The mega doses, of course, were the difficult ones, and the few days after he received each one were pretty miserable for him.

In September, his stomach was robotically removed by the amazing Dr. Tseng. A part of his small intestine became his new stomach and he spent the next several weeks recovering from surgery. This included both tube and TPN (directly to the veins) feeding and was not without complications – a leak, an infection scare, etc.

Being able to eat again has been challenging as he can only eat very small amounts (and so must do so several times a day) and much of the time just hasn't felt that well. Fortunately, this gets better over time.

The good news – Gary's tumor did not like the chemo and all but disappeared as a result of the chemotherapy. The doctors believe that they removed what little was left when they did the surgery and optimism abounds.

Throughout all of this, Anne has been amazing. The fact that she is a dietitian combined with her attention to detail and devotion has made an unbelievable difference in this extremely difficult situation.

THE LATEST NEWS

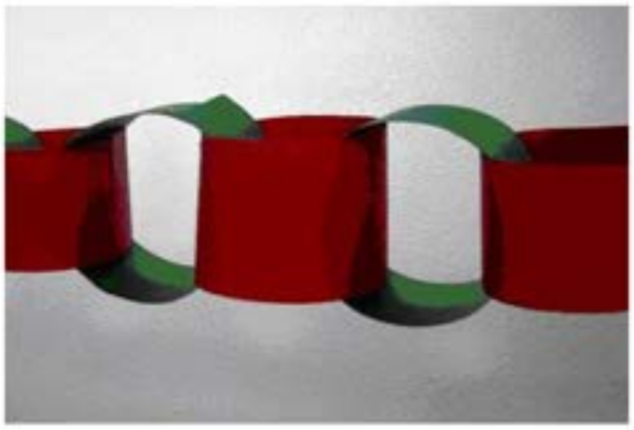
This brings us to where we are today. Gary started his last nine weeks of chemo last Wednesday. Although it is still not easy, this round seems no worse than the first.

Through a combination of new information and trial and error some of the drugs he is taking are not only helping him feel better, but are also allowing him to sleep better at night.

Anne and I have this image of a paper chain in our minds – you know, the kind we used to use as children to count down the days until Christmas.

This chain, instead, counts the days until Gary is finished with his treatment and some normalcy can begin to return to their lives.

There are still several links on the chain, but today there is one fewer than yesterday and tomorrow there will me one fewer than today.



And, there are certainly fewer than there were last spring! Many thanks to all of you for your support, past and future, as the chain gets shorter and shorter.

After Christmas update.

December 26, 2010

Hi, Marcia here with an after Christmas update on the Olsons.

Christmas dinner was at their house yesterday (remarkable, I know!). Their house looked wonderful and Anne prepared a lovely meal complete with delightful party favors.

On the health front, things are not as positive. This latest round of chemo has just been the pits. Gary feels really lousy most of the time and the tube feeding (which is supposed to make up for the calories he's not getting from the little he can eat) is making him feel even worse. Continuing with the tube feeding may not be an option. Understandably, they are both discouraged. Anne will call Dr. Ey tomorrow with the hopes that they can all put their heads together and figure out a way to make this easier.

Brie, crackers, pears repeat…

December 27, 2010

Hi, Marcia here with a Monday update.

Gary is feeling slightly better and they are going to hold off talking to Dr. Ey until their scheduled appointment on Wednesday. Gary is attempting to eat 250 or more calories every hour and is having success with Brie, crackers and pears. Brie, apparently, is right up there in calories with peanut butter and everything at T.G.I. Friday's.

It's still not easy, but it's better.

The latest in transdermal patches: THE BRIE PATCH.

CAUTION: not yet tested on cravings for Fresh Pecorino or any of the blue cheeses...

Picard gets his pink slip.
December 29, 2010

Hi, Marcia here with an update on Gary's appointment with Dr. Ey. Because of Gary's low white blood cell count, Dr. Ey has fired Picard.

They'll wait a week to determine whether or not he'll need the bazillion dollar shot he got last time.

Although his rapid weight lose has slowed, it is clear that Gary is not going to be able to meet his nutritional needs through eating and tube feeding. His body is just not allowing him to eat as much as he needs to and the tube feeding has always made him feel lousy.

As a result, Dr. Ey has decided to put him back on TPN. Whether or not they'll remove the tube now remains to be seen. He'll continue with two more mega doses of chemo but even if his white cell count increases, he won't be able to continue with Picard on a 24/7 basis (having both TPN and Picard's chemo in the port at the same time won't work). Instead, once a week in the doctor's office, Gary will receive the chemo Picard was providing him.

We're sending prayers and positive thoughts/energy that the next seven weeks of chemo won't bring any more challenges, that Gary will quickly feel better, and that eating will become as easy as pie.

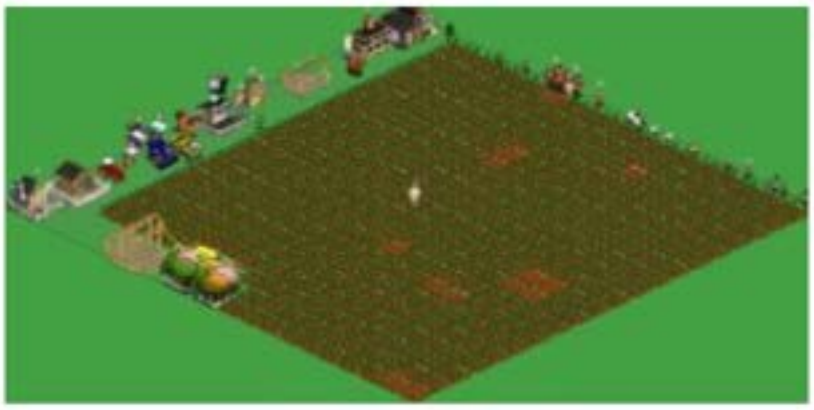
Farmville.

January 2, 2011

The picture to the below is of my farm.

My farm has two orchards, a turkey roost, pig pen, bee hive, two fruit stands, an animal trough, a dairy, and a bakery. It also has a tractor, seeder, and harvester as well as a horse stable and garage that are under construction.

The farm also has 23 neighbors, but I only know three of them personally. Cindy, Linda, and Ed.



You are probably asking yourself “What the heck is he talking about and what does it have to do with cancer?”.

Well, I’m talking about the Facebook game Farmville. Its relation to cancer is that when you’re so ill that your guts are in constant revolt having a mindless diversion is a godsend.

And Farmville is a wonderfully mindless diversion.

I have to admit that though this entire cancer adventure has been an ordeal, this last stretch has been a particular pain in the ass.

Fortunately, I’ve been off chemo for the past four days and am feeling pretty good. Getting the extra nutrition through the TPN is working well and it’s not creating major problems so far.

I had a wonderful time at a New Years party with Linda, Nancy, Ed, and Lisa. I also enjoyed Christmas, though I was still on chemo and had to excuse myself several times to have a private conversation with my stomach. We also had a fun holiday visit with Bill and Dee where my stomach behaved quite nicely.

On Wednesday we will chat with Dr Ey.

We have several issues to discuss.

Since my port is no longer available because of the TPN, there is a possibility I might start getting the 5FU (Picard Juice) in one shot per week rather than as a 24/7 infusion. Another possibility is bagging the 5FU entirely.

There is also the issue of the feeding tube. Though we had the tube replaced, it still doesn't work. My body, which is as stubborn as the rest of me, just won't tolerate being fed that way. We either need to figure a way to get it to work or yank the damn thing out.

I'm confident we'll come up with a workable plan for getting me through the rest of treatment, though I'm not quite certain what it is.

If my white blood cell count is up on Wednesday I will begin my second (and next to last) super duper chemo treatment.

If that's the way it plays out I'll spending a lot of time on the farm.

White blood cell count dance in clinical trials.

January 5, 2011

Hi, Marcia here with an update.

It appears that Louise's white blood cell count dance did the trick. Gary was able to have his next mega dose of chemo today along with the chemo he was previously receiving through Picard. In other good news the nurse said that there should be fewer and less severe side effects from receiving Picard's chemo in one dose rather than 24/7. We're sure that the white blood cell count dance will be in clinical trials by year end.

Gary is unfortunately still having some difficulty and discomfort eating and, through a bit of tenacity on his and Anne's part, he will visit a radiologist at some point in the near future to determine if his feeding tube is going in the wrong direction, is secretly a part of the Borg collective, or is otherwise not behaving like it's supposed to and therefore contributing to his problems.

More news as it's available.

Light at the end of the tunnel.

January 8, 2011

My friend Carl sent me this picture to remind me there IS a light at the end of the tunnel.

According to past experience, today will be the worst day of this round of chemo. So far, that's pretty much the way it's playing out.

Once I survive this I'll only have one more big one to go through and I'll be done.

So there is a bright light at the end to all this.

Thanks Carl for reminding me.

News and update.
January 12, 2011

Hi, Marcia here with an update.

Gary finally had the test today to check his tube feeding tube. Going into it he was extremely nervous as numerous health care professionals had told him that he would need to drink the equivalent of the Hudson River in Barium liquid. This had him extremely concerned since, as we know, eating and drinking even a little bit of anything is a challenge for him.

As it turned out, he didn't have to drink anything. The Barium was put directly into the tube, which only makes sense when you consider the fact that they were doing the test to see what happens to substances after they go into the tube. If Kurt Vonnegut were writing this he would end the paragraph by saying "So it goes".

Anyway, the good news is that there is nothing wrong with the tube and there are no adhesions from that surgery that are causing problems. This means that Gary won't have to have any additional procedures or what not done to fix the problem.

Of course, there was some hope that fixing a problem with the tube might be the magic answer to Gary's eating challenges. We're all praying that once he gets through chemo, those problems will go away on their own. Anne and Gary still don't know if the tube will be taken out now, or left in just in case he needs it.

Someone else told him today (others have mentioned it before) that his regiment of chemo is an especially difficult one. All in all, everyone seems to think he is doing quite well.

If he weren't so exhausted and ready to be finished with all of this, he probably would be proud of himself. We are proud of him.

So, when is he finished? He'll have his last big chemo treatment January 26th. That will be followed by two more Picard chemos – February 2nd and February 9th. Prepare to celebrate.

What we need is a nice Haiku.

January 19, 2011

Hi, Marcia here with a quick update on the Olsons.

I would have loved to do something creative with this post (a nice Haiku comes to mind), but you're getting the following instead.

Anne and Gary met with Dr. Tseng yesterday and it was decided that Gary's feeding tube would remain in for now, just in case he needs it after he's finished with his chemo.

He was scheduled for Picard's dose today but didn't end up getting it. This was due to low platelet and white and red blood cell counts, low blood pressure, mouth sores, etc. This will give him a little extra time between treatments so he can be ready for his last mega dose next Wednesday.

As always, good energy, thoughts, and prayers are appreciated.

So are Haikus.

The manicotti is a hit.

January 27, 2011

Hi, Marcia here with an update. After my previous post you're probably worried that I'm going to suggest your comments be written in iambic pentameter. Don't be – just your well wishes for Gary are enough.

Gary and Anne saw a new doctor yesterday, a nice man who is filling in for Dr. Ey while he's somewhere else. That went well except for the part where they started to follow him into the next examination room. Apparently Dr. Ey always goes with them when then go to the room where Gary gets his chemo. That's not the case with this doctor.

You may have picked up on the fact that that means that Gary was able to receive his last mega dose of chemo yesterday. Although his various "levels" were still down, they were up from last week. The next few days will be crummy, but he's done, done, done with these mega doses! He will potentially still receive one or two more doses of the Picard variety, but each day brings him closer to the end of his treatment!

Then he can concentrate on his eating, which is still a big problem. The good news is that Anne's manicotti is a hit. That not so good news is than he's getting 80% of his calories from TPN. Since eating more continues to be a challenge for him, he has a ways to go before he's able to eat enough on his own to maintain his weight. Being able to do so comfortably would be an added and much appreciated bonus.

Cancer makes a lousy straight man.

February 2, 2011

Hi, Marcia here with an update.

Gary was able to receive his second to the last Picard chemo treatment today. If Anne and Gary weren't so exhausted, they would be elated. When you have had your second to the last treatment, it means that your last treatment is soon to come. Last – happening or coming at the end after all the others. Prepare to celebrate!

In other news, he was actually feeling pretty good last night and had a relatively good appetite today with no icky side effects from eating. We are so very hopeful that once the residual effects of the chemo have worn off, he will feel better and be able to comfortably meet his nutritional needs without the help of TPN or tube feeding (the tube continuous to be an annoying little accessory and one he would prefer to live without).

I've decided that not only does cancer not have a sense of humor, it doesn't even make a good straight man. Not to worry. A couple of days ago I called Anne to have her tell Gary that the 1988 movie Killer Klowns from Outer Space was going to be on TV at midnight that night. I thought that Gary might want to tape it since, according to his Facebook page, it is one of his favorite movies. It should have come as no surprise to me that taping it would not be necessary. Gary owns the DVD. I don't believe that Gary has an extensive or even large collection of movies, and I am of the opinion that cancer is no match for a guy who chooses Killer Klowns as one of the DVDs he owns.

Gary decides it's time to whine. Just a little.

February 8, 2011

When I first started this blog my friend Clarence observed that he thought my positive approach downplayed how difficult what I was experiencing really was.

He believed I wasn't telling the whole story about what a nightmare I must be enduring. He was wrong.

The first nine week round of chemo, with the exceptions of the "big chemos", was like having a mild cold without the cough, fever, and nasal drip. The hardest part about that period was figuring out the routine, getting the damned machines to work, and fear of the unknown.

Post surgery was very difficult, but I was prepared for that. They had me so heavily drugged I wandered around in a daze most of the time doing whatever people told me to do. That was followed by some time off of chemo that was almost almost like a vacation.

Throughout this whole experience there has been very little pain, though considerable discomfort. Most nights I get a solid eleven hours of sleep, with little discomfort, and awake refreshed.

All in all, it hasn't been all that awful. A little awful. But tolerable.

This last round of chemo is different. It is awful.

For one thing, I miss Picard. When I was getting a slow drip of chemo 24/7 it evened out the effect. Now that I get it as a single shot it's like a bolt of lighting from the God of Nausea.

It doesn't help that chemo seems to accumulate in your system making you feel crappier as times goes by. Then there's the fact I've been doing this for a long time and am getting very sick of it.

So, as you've figured from Marcia's posts, I've been having a pretty hard time of it lately. After I get my 5FU shot tomorrow, I'll be having a pretty hard time of it for another two or three weeks. But then, with the exception of breaking in the new stomach, it will be over.

I know some of you worry when I don't put up posts fairly regularly. I imagine you visualizing me writhing in agony unable to get out of bed. That's not the case at all.

Truth of the matter is I don't post because I am a zombie. I am taking heavy duty anti-nausea drugs that leave me brain dead, unable to write a coherent sentence, and pretty much non-functional. Anne tells me what to do, when to do it, and I obey.

Lately my main purpose in life is managing my Farmville Farm, surviving meal times, and not throwing up.

Expectations don't get much lower than that.

No balloons allowed – yet.

February 14, 2011

Hi, Marcia here with a quick update.

Unfortunately, the Olsons are not quite ready to do any celebrating.

There is a certain amount of relief that came with Gary having his LAST chemo treatment last Wednesday, but he feels really, really, really crummy and is not able to eat very much of anything without feeling really, really, really bad.

Although we remain hopeful that all of this is just leftover side effects from the chemo, there is that ever present worry that eating will continue to be difficult for him, he will continue to feel icky, and he will continue to have to be dependent on some sort of supplemental feeding for some unknown amount of time to come.

Please send him (and Anne) your thoughts, prayers, and words of encouragement.

10 - Humor Returns

Strawberry jam – it's a good thing.

February 17, 2011

Hi, Marcia here with an update and a list of things that are going better for the Olsons.

Although he is still extremely tired, Gary had enough energy to walk around the yard.

Yesterday he consumed 866 calories by mouth. That's about three or even four times more than what he was able to eat last week.

He now seems to be able to eat toast. He had strawberry jam on his toast, although one would hope he didn't look as maniacal about it as the girl in the picture does.

Things are far from perfect yet, however his icky reactions when he eats are less icky than they've been in the past.

There is a plan to reduce his caloric intake from TPN by 25% each week. This feels good.

There is still much progress to be made, but things seem, at last, to be headed in the right direction.

Convert that gift card to cash.

February 23, 2011

I strongly recommend if you get a gift card for a total gastrectomy you take it to one of those places that redeems gift cards for cash. Dump that sucker as quick as you can.

I know, a gastrectomy is a glamorous procedure and all the celebrities are getting them, but believe me, you'll be sorry if you redeem that card.

It's been two weeks since my last chemo treatment and I've moved on to training my new stomach.

The direct effects of the chemo are dissipating, but the aftermath of having my cells poisoned still lingers. I am still weak, tired, and light headed, but those are more annoying than anything.

The real challenge is increasing the number of calories I take in by mouth so I can decrease the number I get through TPN. So far we've reduced the TPN calories from 2000 to 1500.

Next week we're going to drop them to 1000 calories. This won't be a problem because I'm already taking in enough calories by mouth to meet that goal. As a consequence, I've actually been gaining weight.

The challenge is that I am still having problems eating and drinking.

If I eat very slow, chewing my food to a mush, and stay seated, things are usually fine. However, if I get up too soon and move around my stomach goes into retching spasms that are quite unpleasant.

Oddly enough, after a bout of retching and belching my stomach feels better and I can eat a fairly large meal without problems.

Since what we laughingly call my stomach is so small, I have to eat many small meals. And since I need to stay seated after each meal to keep from retching, I don’t get around very much. I’m getting in a lot of computer time.

As bad as all this sounds, things are getting better.

My body is slowly healing from the devastating effects of the chemo. Each day, in very small ways, I can tell I am getting better.

I want, once again, to thank everyone for their prayers and support. It has meant a great deal to me and has been an essential part of my healing.

Thank you.

Things are looking up.

March 2, 2011

When you measure the quality of life by the number of times you've retched or thrown up during the day, you have no where to go but up.

Things are looking up.

The stomach is acting up less, I have more energy, my brain is less fuzzy, and I am feeling better overall.

I am off the anti-nausea medication that made my brain so fuzzy, which is a huge relief. I am taking probiotics, which are capsules full of live microorganisms (itty bitty bugs) that help with digestion. I am also taking digestive enzymes.

We are continuing our quest to eliminate my need for TPN feeding. We had already reduced my TPN calorie intake from 2000 calories to 1500. This week we are reducing it to 1000. The next steps are to reduce it to 500 then to none.

Hooray!

In preparation for this I have been eating as much as I can hold, which has been a challenge. But I've gained about ten pounds so I have a head start on the TPN reduction.

Of course, getting off TPN means I can also have the useless feeding tube removed. This will be a huge relief as well as significantly reducing the hassle in our life.

It's been three weeks since I completed chemo. They say it takes about two months to heal from the therapy, though it may take up to a year before I feel vibrant.

Actually, I wasn’t too vibrant before so I’m looking forward to what that might feel like.

In another four weeks my hair should start growing back. I never completely lost my hair with this round of chemo, though my scalp is visible from about any angle. I’m looking forward to being hairy again.

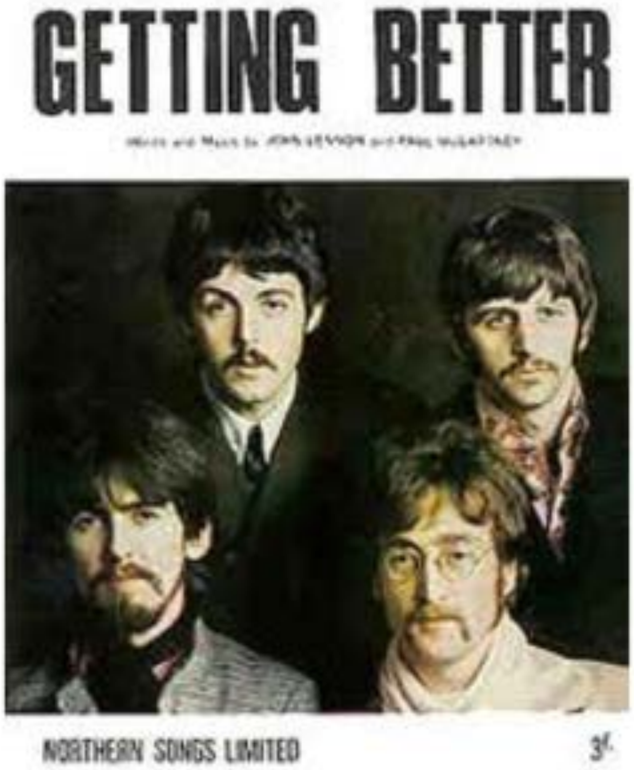
So that’s the latest. I’m feeling better, but there’s still a ways to go.

Thanks to all of you for hanging in there with us and offering your support. You have no idea how important that has been to us. It is what has gotten us through this.

Getting better all the time.

March 9, 2011

Though I still feel pretty crappy, things are getting better.



Last night was my first night on 500 calories of TPN. Actually, it was 250 calories because the pump malfunctioned at 11:30, 1:00 AM, and 1:30 AM. After the third malfunction we shut the pump off and disconnected TPN.

I'm taking in enough calories by mouth that I was gaining weight on the 1000 calories of TPN. We figure I should be able to get through this week of 500 calories without losing any weight.

The trick is I have to increase my calorie intake enough this week to be totally off TPN by next week. This promises to be a challenge.

Another good thing is I've increased the amount of exercise I do every day. I take Molly for a short walk every morning and we take her for about a nine block walk every afternoon. This is a huge improvement from when I could barely get out of my chair.

Though I don't feel all that great most of the time, there are windows where my head clears, my stomach is settled, and life seems pretty normal.

Not surprisingly, this whole experience is getting old. I am so ready to move on.

TPN dependency. A tough habit to break.

March 15, 2011

It looks like it's going to take a little longer to get off of TPN than we had hoped. We were hoping to be off after an additional week but that isn't looking too realistic.

To get off TPN I need to take in a minimum of 2200 calories per day. The ultimate goal is to add another 200 calories, bringing it up to 2400 calories. So far I've managed 2000 calories in a day, but adding that last 200 to 400 is a real bear.

Complicating matters is I'm beginning to get dehydrated. That means I need to drink more liquids, which my already taxed stomach isn't taking kindly to.

Fortunately, Anne has turned into Super Nutritionist and is charting the way. She has come up with a variety meals that are packed with calories yet small enough for my tiny stomach to tolerate.

The challenge is to crowd as many meals into each day as possible without making me sick. If the meals are spaced too closely together my stomach revolts. If they are spaced too far apart I don't get the calories I need.

Anne meticulously charts everything I eat, when I ate it, and how my stomach reacted to it. If a particular food doesn't work she goes back over her notes looking for a pattern. When she finds one she adjusts the food or eating schedule to fix the problem.

Her system is entirely responsible for my increasing my calorie intake so quickly. If it were entirely left up to me I'd be lost.

Though we are encouraged by my increased calorie intake, we’ve concluded I’m not quite ready to go entirely off the TPN.

Even though the TPN only provides 500 calories, cramming that much additional food into my system just isn’t practical yet.

None-the-less, we are making steady progress. We hope I’ll be TPN free after an additional week or so

Tube free.

March 22, 2011

We visited Dr. Tseng today.

He appeared astounded that I was eating 2000 calories a day by mouth and only taking in 500 through TPN. I suspect many people would take much more time to get to where I am. It is an advantage to be married to a former nutritionist.

He agreed it was time to take out the feeding tube. It is gone. I am tube free.

Unfortunately, when he removed the tube the juices from my gut leaked all over my pants. He tried to staunch the flow with absorbent pads. When that didn't work he decided to let it drain into an old fashioned bed pan.

It was very classy.

When the flow stopped he decided to cauterize the wound. He took a branding iron that had been in a camp fire until it was heated to a red hot glow and pressed it to the wound.

Well that isn't exactly what happened.

What really happened was he took this little stick that had some chemicals on it and touched it to the wound to cauterize it. It was pretty boring. The branding iron version made for a better story.

So now I have a hole in my stomach that should heal in a few days, but no tube. Yea.

Another encouraging thing he said was that the positive results of my first round of chemo was very very encouraging in terms of my long term survival. He's said this before, but it was good hear it again.

So every year for the next five years I'll get a CAT scan and an endoscopy to see if any cancer is detected. If there is no recurrence within three years the odds are I am cured.

Now that's good news.

Bullet holes.

March 30, 2011

There is a hole in my gut where they took out the feeding tube that looks exactly like a bullet hole. This is almost as cool as owning a car with the fake gangster bullet holes that hip little old ladies drive.

Today I had my port deaccessed, so I am officially off TPN. The fact that there are no longer any tubes attached to my body makes me feel downright human.

We are having Option Care keep their case open so if I have problems and need to go back on TPN I can. We're not anticipating that is going to happen, but it's good to have a backup plan.

It continues to be a struggle to get in the number of calories I need to maintain my weight. This new stomach continues to be finicky and unpredictable.

It is hard to make it happy.

None-the-less, every week I feel a little better and by summer things should be in pretty good shape.

The only down side is I just learned that on December 21, 2012 the Earth is going to be destroyed by a passing planet named Nibiru or by a black hole.

After all I've been through, I was hoping to be around longer than that.

Drat!

Thank You Marcia.

April 1, 2011

I figured it was past time to thank Marcia for keeping this blog going when I was too out of it to post.

She took over the blog and kept everyone up to date while I lolly gaged at the hospital, watched stupid movies, and waited for my sense of humor to return.

Without her involvement you would all have been left in the dark because you better believe I wasn't up to writing anything that wasn't drab and depressing. Or writing anything at all, for that matter.

Best of all, Marcia was able to maintain the humorous tone I had worked to establish for the blog. You will find this hard to believe, but some people can't find any humor in cancer at all. We were all fortunate Marcia "got" the tone I was attempting to maintain.

Many of you have commented that this blog has been a wonderful tool for keeping people informed. No one wants to pester a family undergoing cancer treatment with emails asking what is going on, yet people want to know. This blog has been the perfect way to let people know where things were at. When people wanted information the most, I was least able to provide it. Marcia stepped in and provided you with what you needed to know.

She did neglect to mention my first sponge bath, my inability to keep the back flap of my hospital gown flapped, or the time I shot white fluid at the x-ray technician through my nose. But then, she probably figured you didn't really need to know that stuff.

So I figure we all owe Marcia a debt of gratitude for keeping people informed.

Thank You Marcia.

11 - Stomach In Training

Chained To A Chair.
April 13, 2011

I am probably the only person in Western Oregon not depressed by the record low temperatures and persistent rain.

When you're feeling crappy, sunshine just reminds you of all the fun things you could be doing if you had any energy. Crappy weather and feeling crappy go well together.

Don't get me wrong. Things are better than during the surgery and the worst of the chemo, but recovery has not been as snappy as I had hoped.

I'm not snappy at all.

I'm having a heck of a time adjusting to the new stomach. To get in the 2400 calories a day I need to keep from losing weight I need to constantly focus on food.

I need to eat many times a day. After each meal I usually need to sit for quite awhile or my stomach rebells. Walking around too soon often has dire consequences.

It makes me feel like I am chained to a chair.

I also underestimated the impact the chemo and surgery would have on my stamina. I thought I'd bounce back quicker.

On a very good day running errands for a couple of hours pushes my limits. After that I am usually, though not always, shot for the rest of the day.

Streaming video from Netflicks keeps me sane. Netflicks now pretty much has video on demand. It's great, assuming you're not bothered by watching it on a small screen. Which I am not.

I've re-watched many of my favorite Arnold Schwarzenegger and Bruce Willis movies. I have also tried a variety of random movies I wouldn't normally consider watching.

I've also been enjoying watching vintage television shows like Alfred Hitchcock, Twilight Zone, Have Gun Will Travel, Andy Griffith, and Gunsmoke.

If you're going to be chained to a chair you may as well be entertained. Fortunately, I'm not distracted by thoughts that it would be better if I were out in the warm sun. The warm weather would be wasted on me.

In that regard, I am better off than my Oregon neighbors.

(This post is written in e-prime, a version of the English language that excludes all forms of the verb "to be.")

A New Direction.

April 27, 2011

Linda, Hugo, and Sarah have all expressed concerns because I haven't posted in a few weeks.

I guess that's understandable considering in the last episode I was chained to a chair with no chance of escape. Things have gotten better. The chain has been replaced by a rope.

Escape seems possible.

One reason I hesitated posting was because Anne pointed out people were getting burned out on the blog because reading about cancer for so many months gets depressing. On Saturday it will be the one year anniversary of my diagnosis, which is an awfully long time.

She suggested I do an upbeat post that emphasized the positive. With the depressing weather, stress from extended family, and an inability to maintain my weight I was having problems finding my happy spot.

We visited Dr. Tseng yesterday and it was a bit of a turning point. I haven't exactly found my happy spot, but things are looking much better.

In fact, I feel like I am finally headed in a new direction. A direction that will lead to life becoming normal again.

For one thing, Dr. Tseng said to stop worrying about the slight weight loss. He said he wouldn't be concerned unless I'd lost ten to fifteen pounds, which isn't going to happen.

He also strongly encouraged me to crank up my exercising, both to build muscle mass as well as increase my appetite. I immediately started doing push ups, side planks, and stretching exercises. I'm also going to increase the intensity of my walks.

I'm pretty excited about this. I miss being fit.

I mentioned to Dr. Tseng my heart had been fluctuating between 84 and 119. A normal a heart rate is between 60 and 100. He said this was probably due to my body readjusting after the surgery and chemo. He also said it could explain why I felt so crappy and maybe why I am still retching.

He suggested I visit my cardiologist, which I am doing on Monday. Maybe that will help.

Almost every time I eat I have a negative experience. I'm afraid my body has become so conditioned to feeling bad when I eat that it has decided that's the normal thing to do. It's one of those psychological things.

I'm going to deal with this by checking out a clinical psychologist that specializes in psychoneuroimmunology, the science of mind/body medicine.

She has a history of working with cancer patients to help them work through the after effects of treatment. She uses a combination of Jungian therapy, visualization and hypnosis to achieve her goals.

Considering Jungian therapists tend to be nuttier than a fruitcake, this promises to be immensely entertaining.

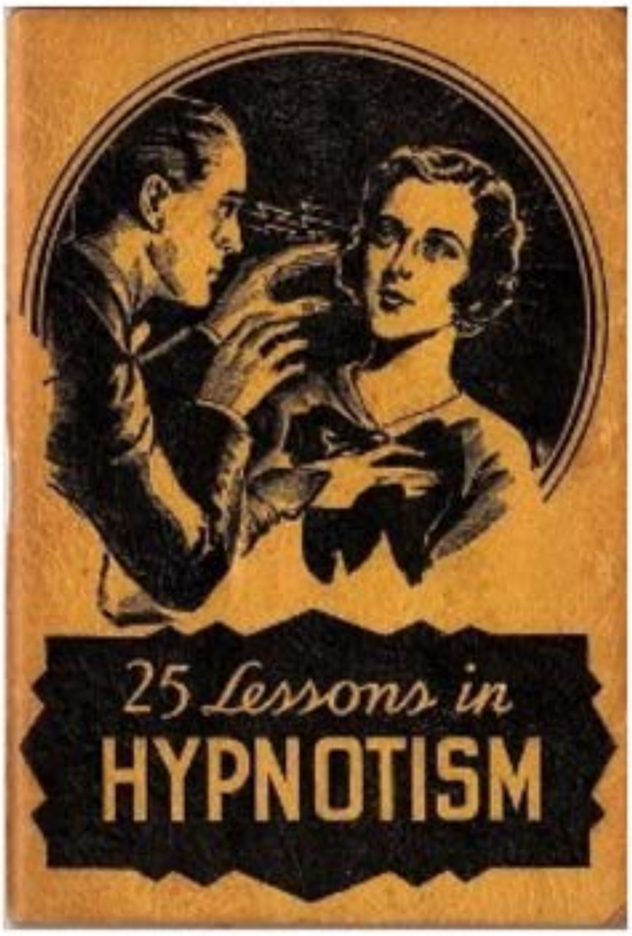
Hypnotized.

May 7, 2011

As I mentioned, I got hypnotized. Every time I hear the word orinthophobia I have an uncontrollable urge to quack like a duck.

Of course, I quacked like a duck every time I heard the word orinthophobia prior to getting hypnotized, so it might be a coincidence. But you never know.

Other than the duck thing, the hypnosis seems to be working. A focus of the hypnosis was to help me enjoy food again. That part seems to be working.



Lately I've been really enjoying the taste of food, though the digestion part is still a challenge.

I bought some grapes the other day and have been savoring them. The taste is marvelous. I eat one grape at a time and allow some digestion time before trying another.

I've also been enjoying the taste of a Full Sail Pale Ale. I've been working on the same bottle of beer for three days, and it's still half full, but I enjoy every sip.

Today I fixed myself a hamburger sandwich. It was delicious. Or at least as much as I could eat was delicious.

The digesting part didn’t go too well, and I wasn’t able to finish the sandwich, but the taste was great.

Relearning how to enjoy food was a major part of the hypnosis session.

It is definitely working.

Another benefit of the hypnosis is it is helping with the fatigue. It’s not supposed to help with the fatigue. There is nothing in the auto-suggestion that relates to fatigue. But the deep relaxation the hypnosis creates seems to lessen it.

That’s an unanticipated benefit that is greatly appreciated.

On a somewhat tangential matter, the common symptoms of orinthophobia (fear of ducks) are shortness of breath, rapid breathing, irregular heart beat, nausea, vomiting or an overall feeling of dread.

I noticed these are also the symptoms of cancer treatment.

I wonder if the two could be related?

Hair, Hypnotism, and Belly Fat.

May 15, 2011

As you can see, the hair is starting to grow back.

It seems to be starting with the mustache which is now bushier than ever, followed by the beard which is getting longer, and, finally, the hair on my head which is getting longer and thicker.

Chest and other previously hairy body parts are also returning to normal.

“Give me a head with hair, long beautiful hair
Shining, gleaming, streaming, flaxen, waxen
Give me down to there, hair, shoulder length or longer
Here baby, there, momma, everywhere, daddy, daddy.”

Ah, I’ve been so nostalgic for my full head of hair. It won’t be long now. I’m sure my barber wonders where the heck I’ve been. The poor guy probably misses me.

After the first round of chemo I had really curly hair. That didn’t happen this time. My hair appears pretty much like it always has been, though perhaps a bit grayer.

I can’t imagine why this experience would turn me grayer.

My weight has dropped from 210 lbs to 180. According to the charts the healthy weight for a 6′ 3″ guy with a medium frame is between 167 to 182.

I guess that means I have a healthy weight, though it seems a little skinny to me. I do have a little belly fat in reserve, which I find strangely comforting.

I had been losing about a pound a week, but that seems to have stabilized. Better yet, it's stabilized while I've been eating more fruits and vegetables and exercising more.

It almost seems un-American to be this thin.

When I first started exercising again I could barely do one push up. Now I can barely do ten. I've also increased the intensity and length of my walks. Pretty soon I'm going to start swimming again.

Things are returning to normal.

Many of you seem curious about the hypnosis. At first I didn't notice any results from it at all.

Then one day I ate this grape and went "Wow! That tastes really great!". After that I noticed that most foods were tasting better. It finally dawned on me that a major focus of the hypnosis was to improve the taste of food.

It must be working.

I've also noticed I have more energy and stamina, my head is clearer, and I'm getting more done. Not that I'm getting all that much done. The fatigue is still an issue, but even that is getting better.

Though recovering from the cancer treatment continues to have its challenges, there have been major improvements even within the past week.

Things really are getting better. Much better.

Swimming.

May 24, 2011

This week I was back to swimming 40 minutes a day.

I didn't have a picture of myself in my swim suit since I lost so much weight, but I look pretty much like the picture below.

Oh, OK, I don't really look like that, but I'm slimmer and trimmer than I was.

Before I started swimming my weight had stabilized at 180 pounds. After a week of swimming it dropped to 178.

I figure that's not a problem since the ideal weight for someone my size is between 167 and 182.

My energy level is continuing to increase and I am actually getting stuff done.

Today we visited Dr. Tseng to have my port surgically removed. What this means, of course, is that the last of my Borg implants are now gone.

Hooray!

Removing the port was a relatively painless office procedure that only took a few minutes. Dr. Tseng did it while wearing his business suit. He's funny that way.

The only down side is I'm not allowed to swim for a month. It's an avoiding infection thing. Those pool guys are pretty germy.

A week in La Grande.

June 6, 2011

We just got back from spending a week in our house in LaGrande. This was the first time I've felt up to the trip in over ten months.

It was a wonderful trip.

It was difficult keeping my calories up during the five hour drive. Moving cars are notoriously challenging for sensitive stomachs.

Consequently, I didn't eat as much I would have preferred on the trip over or back. This might account for some of the weight loss I experienced from the trip.

None-the-less, while there I ate a steak and eggs breakfast, had a Pizza night, and had Thai food. I don't recommend LaGrande for Thai food.

Pizza yes, Steak yes, Thai no.

I was pleased with my energy level while in LaGrande.

We did a lot of yard work, which was mostly lawn mowing, weed pulling, and hauling yard debris to recycling. I got a lot more done than I had expected.

We don't have a weight scale in LaGrande, so I wasn't able to track my weight while there. When we got back I was appalled to learn I'd dropped from 178 pounds to 173.

I'd lost five pounds in seven days! Yikes!

As I said in my last post, the ideal weight for someone my height and body build is between 167 and 182 pounds. I’m still within that range, but I get nervous when I have these sudden weight losses.

The good news is that since returning from La Grande my weight has maintained at the 173 pound level.

Another positive is I look pretty darned good at 173 pounds. Being forced to buy all new clothes makes me look even better.Without clothes I look pretty scrawny. Fortunately, there are limited social actives I engage in that do not require clothes. It works out pretty well that way.

I can see the challenge is going to be balancing how much I exercise, eat, and do other activities.

Eating is the primary challenge and some days are more difficult than others.

Occasionally I can eat a relatively large meal in a reasonable amount of time. More often it takes me about an hour to eat a meal or even drink a glass of milk.

Considering I have to eat five or six times a day this can really cut into my plans.

This limits what I can do. For example, I will not be running any marathons any time soon. Of course, I wasn’t running any marathons before, so some things haven’t changed.

Feed Me!

June 10, 2011

I was suddenly hungry.

I haven't been suddenly hungry in over ten months. It was a full fledged low blood sugar attack.

Light headed, wobbly knees, ravenous appetite.

I stopped gardening and headed for the kitchen. I actually scarfed food, which wasn't a good idea. I knew at the time it wasn't a good idea, but I couldn't stop.

After I ate a bit my head cleared and I stopped being wobbly. The blood sugar had returned to normal.

I see this as an extremely good sign.

It means my body's natural regulating systems are kicking back online. My body is saying "enough already with all this weight loss".

This has happened to me twice over the past week. I've also gained half a pound over the same amount of time.

Slowly but surely things are returning to normal.

I ate a hamburger!!!

June 13, 2011

I know, for you eating a hamburger is nothing. An every day experience. But for me it was a milestone.

When I was being fed through a tube sticking into my neck, not taking any calories by mouth, hamburgers were a re-occurring fantasy.

I'd imagine the meat cooking, putting the sandwich together, that first bite. I'd run the fantasy over and over in my head.

Yesterday I went to a birthday party that featured barbecued hamburgers and hot dogs. It was difficult to choose. I've been craving hot dogs as well, and they would be less challenging to digest, but I decided to go for it.

I chose the hamburger.

They had large buns which I generously slathered with mayonnaise, built on a bed of lettuce, added two generous slabs of tomato, topped with the hamburger patty, covered with sweet pickle relish, and slathered with Heinze catsup.

Now that is what I consider a classic hamburger. It was wonderful.
I can not tell you how much pleasure it gave me to bite into this masterpiece. And what is amazing is I was almost able to eat the whole thing. Almost.

It was quite the experience.

Greasy mayonnaise and catsup leaked out onto my fingers and had to be surreptitiously removed with my tongue. Surreptitiously because Anne has this thing about using napkins, particularly in public.

Personally I find finger licking part of the artistry of the perfect hamburger.

I was discreet, but I licked.

I can not imagine my week getting any better than taking the first bite into that wonderful burger.

But who knows, the week is young.

Strawberry Waffles

June 15, 2011

I know, most of you don't give a rip about what I eat.

But in Linda H's last comment she said "Please post more food fantasies-turned realities as the weeks goes on. It helps us enjoy our food more!" So if you don't want to read about my eating habits, blame her.

I had a strawberry waffle this morning. It was wonderful. Not as wonderful as the recent hamburger, but wonderful none-the-less.

The image below is a picture of the actual waffle. I took the picture with my iPhone. The iPhone is my favorite new toy.

Anne and I have somewhat of a ritual of getting fresh strawberry waffles at Davidson's Family Restaurant in Tigard. Most of their food is typical family restaurant fare, but their fresh strawberry waffles are exceptional.

Anne and I have had breakfast there, during strawberry season, for years. Many many years, in fact.

One of my customized hypnosis mp3's specifically implanted in my subconscious that one day soon I would be able the enjoy a strawberry waffle.

That day was today.

Live Update – Hooked to a tube again.
July 6, 2011

Here I am again at the Knight Cancer Center (Pacific Oncology) attached to another IV drip.

As you can see, it had to be plugged into my arm since there is no longer a port. I had the port removed about six weeks ago.

The reason for my return to Borg reality is because my red blood count is low. I am getting a massive infusion of iron, which is known for building red blood cells.

If this works, and it should, I will will feel better and have less fatigue.

The whole process takes four hours, so I should be out of here in about fifteen minutes.

This is good other than it is hot outside and I'm rather enjoying the air conditioning. The cool comfort almost makes it worth being hooked up to a tube.

Iron Man.

July 17, 2011

My last post on getting the IV iron infusion prompted Marcia to observe she was surprised I missed the obvious Iron Man reference.

Embarrassing.

None-the-less, I figure it is not too late. I'll just pretend I was saving it for this post. Which, of course, I was.

Though I felt crappy for a few days after the infusion the beneficial effects seem to be kicking in. I am already less fatigued. This should get even better over the next few weeks.

In other words, I will soon be a full fledged Iron Man.

Adding balance to this good news is that I am experiencing Lorazapam withdrawal.

Lorazapam is usually used as an anti-anxiety medication. In my case it was prescribed for it's anti-nausea benefits.

I stopped using it during the day because it made me stupid. I continued taking it before bed because it settled my stomach, made it easier to sleep, and being stupid is less important when you are asleep.

I started to realize it was making it too much easier to sleep. I was looking forward to it a bit too much.

I decided it was time to look into it more. I learned people easily became dependent on the drug as well as it having tons of really nasty long term side effects.

I decided it was time to say goodbye to my new friend.

At my doctors' recommendation, I reduced my dose by fifty percent for a week, then totally stopped taking it.

Some of the potential side effects of withdrawal are decreased appetite, difficulty sleeping, rapid weight loss, anxiety, nausea, and vomiting.

I've had all of these, but can't tell which are from the lorazapam withdrawal and which are just left over from the cancer treatment. I'm hoping it's the lorazapam withdrawal because the symptoms would likely go away quicker. I think.

I've also been concerned about my weight loss. I am now at 167 pounds, which is at the lower end of what a healthy weight is for someone my height and body build. I've been losing about two pounds a month and nothing I've tried so far has stopped the loss.

None of my doctors seem particularly concerned. I think a self regulating mechanism will kick in pretty soon and my weight will stabilize. I'll be relieved when it does.

On an unrelated topic, my hair is growing back thicker, darker, and curlier. Combined with my trim physique I am looking pretty sharp.

Everyone comments on how good I look, which I can see it in the mirror. So along with everything else I've had to deal with I now have to cope with vanity.

Ups and Downs.

July 31, 2011

There have been some ups and downs recently, but I'm doing pretty good now. My energy level is up, digestion is OK, and I've got more of an ability to drink water than I've had in months.

That is really nice.

The "down" has mostly been from problems withdrawing from the drug Lorazapam, which I referred to in my last post.

When I needed drugs for nausea to just get me through the day they had me on Lorazapam three times a day. It was pretty awful.

It filled my brain with a cotton ball substance so thick that thoughts could not penetrate it. I couldn't follow what people were saying and the stuff I came up with to say didn't make much sense. At least that's what I am told.

It was like buying a severe mental handicap in a bottle. And I was paying good money for it.

I stopped taking the stuff except at bedtime. Lorazapam made it easier to sleep and I didn't mind so much not thinking clearly when I was asleep.

I got to liking the stuff a bit too much and soon realized drug dependency was one of its many characteristics.

I tried tapering off from 1 mg at night to 0.5 mg. That wasn't too bad. However when I totally went of it I got really sick. Sleeplessness, inability to find words, fuzzy brain, nausea, and vomiting. It was ugly.

I’m now back on 0.5 mg and doing much better.

My plan is continue with the 0.5 mg but gradually shave small amounts off the pill with a razor blade. I figure if I cut back gradually enough it will trick my body into not noticing the drug is going away.

I hope my body is dumb enough to fall for that trick. I am trusting all of you to not tip it off to what I am doing.

It seems there should be a cool name for shaving pills to gradually reduce drug dosage. Something like “pill blading” or “dose slicing”, but I’m not aware of any such commonly accepted phrase.

If there were such a phrase the English language would be better for it. Unfortunately, I have enough on my hands without trying to fix our language at the same time.

So to wrap up, I’m gradually withdrawing from a nasty drug, feeling pretty good considering the circumstances, and noticing that life is generally getting better.

It helps to know that you are still reading the blog and sending positive thoughts. It is greatly appreciated.

12 - The Homestretch

Looking pretty darned good, all things considered.
August 2, 2011

I've been grumbling a lot lately about how difficult things have been.

I figured I'd post this picture to show you I look in better shape than I sound.

This is what I look like after not having had my hair cut for over a year.

The chemo made most of my hair fall out, though not enough to make it worth shaving my head. When it grew back it had more curls than at any time in my life.

There are two schools of opinion about whether the hair will remain curly. Some people say it will. Others say that as you get it cut it will revert to how curly it was before.

A really good week.

August 11, 2011

I had a really good week.

Admittedly, when most people say they had a good week their week didn't include fatigue, retching, and vomiting. But I live by a different standard.

This week was good because I just overall felt better. More energy, more stamina, more zest for life.

My stomach has not been continually upset, I could eat most meals with out my stomach revolting at the beginning of the meal, and I just generally felt better.

I don't have an explanation for why things are better. It might be because I stopped taking Zofran. Or maybe because I am gently easing of of Lorazapam. Or maybe it's just a quirk of fate.

Whatever the cause, it is encouraging.

Door Number Three!!!!!

September 2, 2011

Everyone knows the stories that involve three doors.

The hero of the story is faced with three doors. He gets whatever is behind one of the doors. Two of the doors have something awful behind them, the third something wonderful.

Today I lived the story.

Earlier this week I went in for my one year post surgery CAT scan. The possible results constituted the three doors.

Door Number One: Treatment didn't work, the cancer had spread, I am going to die.

Door Number Two: They found something in the results that is very concerning, but aren't certain what it means. They want to monitor it with frequent CAT scans, which means we will be nervous wrecks until it gets figure out.

Door Number Three: There is no sign of cancer and everything is fine.

Clarence is upset.

September 24, 2011

Clarence, one of my swimming buddies from the pool, is upset because I haven't posted to this blog for awhile.

I pointed out this was because everything was fine and there wasn't anything to post about. He wasn't satisfied. John agreed with him. John said he checks the blog five or six times a day and was disappointed to find nothing new.

Five or six times a days? I don't think so. He watches me swim laps for forty minutes every day and must notice I'm not at death's door. John exaggerates, sometimes even lies.

But peer pressure is irresistible, so I am posting.

I already mentioned that the results of my CAT scan showed no new cancer, which is obviously good news. Since then we've met with Dr Ey, the oncologist, who says being cancer free after the one year from surgery CAT scan is major good news. If the cancer is going to reappear it is most likely to have shown up within the first year, which it hasn't.

After that the odds of it coming back dramatically drop. That doesn't mean the danger is past, but it does mean things are looking very good.

I have been having challenges with acid reflux, which is basically really bad heart burn. Actually it's more complicated than that, but that gives you the general idea. This is something I'm going to be coping with for the rest of my life.

Managing acid reflux is basically a balancing act.

I need to eat many small meals, that are evenly spaced throughout the day, that don't include too many foods that are hard on my stomach. What is hard on my stomach can change from day to day or hour to hour. Which makes it a challenge.

I also am trying to stabilize my stomach by taking digestive enzymes, probiotics, and various other over the counter medications that keep my tummy from tumbling into terrible trouble. Also known as the 4 T's.

Keeping this all in balance is something I will master over time, but at the moment it is a struggle.

As I'd mentioned in a previous post, I've been having trouble withdrawing from the medication Lorazapam. I've been cutting back the dose very gradually and am now down to 1/4 of a milligram per day. The gradual withdrawal is working. I'm confident I can kick this drug without too much trouble.

Unfortunately, I am now addicted to butter rum flavored life savers, which I now buy in bulk.

Thanks a lot Carl.

Wood Pile.
October 8, 2011

People keep saying I should post something to this blog, but there really isn't much to say. So I'm going to write about my wood pile.

Every year we get a cord of wood which I stack into a neat cube, as you can see below.

If you would like to see how I stack it (and I don't know why you would) watch my Youtube video:

[How to stack a wood pile in a way that it doesn't fall down.]()

At last count the video has been watched 20,300 times.

"What does stacking wood have to do with recovering from cancer treatment?" you ask.

A lot. The main thing being that I have enough energy and stamina to do it. Well, maybe not stamina so much. It took me a day and a half, with lots of breaks, to get it stacked.

But the point is I got it stacked.

What was nice is it seemed to make the neighbors feel good to see me out there stacking wood. Several commented on how I must be feeling much better to be taking on such a project.

They are right.

Lorazapam Free!

November 1, 2011

John and Clarence, from the pool, have been hounding me, again, to post something on the blog.

I keep telling them there isn't anything to report and if they wanted to know how I'm doing they could just ask. After all, I am standing right there.

But they insist on a blog update. So here it is.

I am finally off the nasty drug lorazapam. After very gradually reducing the dosage to 1/4 of a milligram a day I finally went cold turkey. I felt rather shaky for a few days but everything is fine now.

I continue to feel better all the time. I'm still fatigued at times, but overall have more energy. Some days are better than others, but for the most part life is going well.

I still have an upset stomach fairly frequently, but it is manageable. It seems that with only a small pouch, rather than a full size stomach, gas pressure builds up rapidly. It's nothing a good belch can't cure. Actually the belch is more like a retch, but it feels much better afterwards.

That's probably more than you wanted to know. Blame John and Clarence. They are the ones who made me do this.

The End.

November 30, 2011

Just as all good thing must come to an end, so too must bad things.

I have completed cancer treatment and by all measures things are going well.

Presuming there are no nasty surprises lurking in the future, I am cured. Of course it's too early to presume that, but I can hope.

Though I continue having minor challenges breaking in the new stomach, these seem too inconsequential to warrant a blog post.

I have decided to end the blog with this post.

Once again, I would like to thank all of you who have stood by us during this ordeal.

I can never tell you how important this has been for us.

Thank you.

Afterword

Gary always said he was dammed if he was going to let stomach cancer kill him, and it didn't. Unfortunately, sudden cardiac arrest did.

Gary was nearly four years out from his stomach cancer diagnosis and had no known cancer recurrence when he died. He was 65. His mother had also died of sudden cardiac arrest in her mid-sixties.

He would want those reading this e-book to see it as a message of hope that it is possible to survive stomach cancer and once again enjoy life. Watch this YouTube video to see the fun Gary was having less than three weeks before his death.