

Journal

Leaving Cape Cod Hospital

August 7, 2011

After leaving the CCH (Cape Cod Hospital) we (Carol and Fred) were in total shock. Carol was devastated and just knew she had cancer that spread to the brain and she is going to die. I drove white knuckled down rte 28 back towards the grove. We both broke into uncontrollable bouts of tears. She said we need to pull over and talk. I wasn't about to pull over just anywhere and tried to think....where....where do I go? As we approached the Bass river bridge I thought to myself and decided to go to the West Dennis Beach, it's a huge long parking lot facing the ocean and it's getting late so there shouldn't be too many people around. We pulled into the parking lot and I found a fairly wide stretch we could call our own so I parked the truck facing the water and we collapsed in each other's arms and let it all out. I can't imagine what was going through Carol's head at that moment but can only guess her life was flashing before her eyes with all the horror, concern and what the future will hold.

I think it was at this moment in time I realised how important love is and what really matters in life. It's not the day to day trials and tribulations but the deep bond two people have that was set a long time ago and somehow gets buried under all the petty things that pile up over such a long period of time you don't even see it happening.

After smoking almost a whole pack of cigarettes between us in about an hour or so (ironic isn't it?) and filling buckets with tears. We made a few phone calls to family to let them know we were in trouble and tried to regain our composure before we headed back to the grove.

We decided it best to just pack up our clothes and personal necessities and head home that night leaving Kristen there instead of dragging her home to what? When we got back to the cottage we told Kristen that the hospital did some tests and Carol had something on her lung and in the head. We told her that we would drive back home to get the proper help. After letting close relatives (in the grove next to us) know what was going on we packed up and headed home. The drive home was mostly silent, dotted with outbursts of tears. We arrived home in Ashland, each of us had a glass of wine and *tried* to retire for the night thinking we would form a plan of action in the morning.

Family Gathering - What To Do ?

August 8, 2011

Monday morning came, not much sleep was had. I started the day by giving Carol an anniversary card I had already tucked away earlier in the week. It's our 30th anniversary today and this is what we get. Carol and I have been together for 37 years actually, we got our first apartment when I was still a senior in high school. She is the older one, had already graduated and had a full time job. I remember it was strange that I got up and went to school while she went off to work.

Family arrived at the house and we told them the details that we had, they were all comforting and wanted to help in any way they could. We got the name of a couple contacts that were highly recommended. I called into our primary care Dom Chira's office and spoke with his admin. I told her about what had been going on and asked if she could contact and make an appointment with a specialist. The office called back in about 1/2 hour, she informed me that the point contact person was not in today and the name of the replacement was not returning any calls. That really disturbed me and brought the panic level up a bit. After more discussion with family my brother Bob suggested calling our cousin MaryAnn who's daughter Tara is an ER Doctor at UMass Medical. Another call from Chira's office brought no good news, just another "they are not returning the calls" message. I called MaryAnn and filled her in where we were and said she would call Tara for us. Tara called back immediately and I filled her in. She tried to get us in at Marlboro but was unsuccessful. She suggested that the best thing to do was to get Carol into Brigham and Womens or Mass General and enter through the ER. We all decided that would be the best thing to do at this point, to get Carol into the system and get things moving forward. Carol and I packed an overnight bag and headed into MGH.

We checked in at the MGH ER entrance around 1 or 2 pm. After initial check in we sat in the waiting area waiting to be called up and give the details. Only 15 mins or so passed and we were called up to sit with the woman who would take the details. Carol was sitting in the only chair while I stood beside her. After giving the basic details, name, DOB, etc. the woman started gathering more of the chain of events that led us here. While I was looking around out at the waiting area with my back slightly turned on Carol, all of a sudden I'm feeling this prodding on my backside. I turned around to look at Carol and I was shocked to see her having some sort of an episode. Her face was all locked up, her eyes locked open, and she was trying to stick out her tongue to which I spotted this round white thing on the end of. I later learned she had put an Altoid mint in

her mouth worried about bad breath. She couldn't speak and all I could think was she's having a stroke. I actually started yelling "she's having a stroke"! to which the nurses responded by pulling me back off her and assuring me she was not having a stroke. I was scared at this point and lots of activity started to insue. They got her in a wheelchair real quick and proceeded to bring her back into the Urgent Care area of the ER. Her episodod lasted for minutes and didn't subside till we were sitting a while down in the Urgent Care area. She appeared to recover but was now having trouble speaking whole sentences and her face looked a little droopy on the right side. Needless to say the emotions we both were feeling now were through the roof !

It took awhile but soon after that she was brought into one of the treatment bay areas where she was immediately attended to. The attending nurses and staff were all very friendly,professional and compassionate. The ER attending doctor finally came in and we gave him the story and also gave him the dvd disc with imaging we had from CCH. He got that into the system right away meanwhile the traffic increased around Carol. MGH is a teaching hospital so there were many different people coming through from all different areas of medicine. They kept doing neurological exams over and over by different people.

Erin came in after some time with a rollaround piece of equipment that had a laptop on the top. She asked if we wanted to see and go over the images that were taken at CCH. Carol and I both said yes. Erin asked how much did we want to know and we said not to sugar coat it, tell us like it is. She called the images up that we had already reviewed at CCH and went through them basically confirming what we already had heard. There is a mass on the lung and a mass in the brain and the next step would be to have an MRI done. That was scheduled and we waited. So at 4:45pm we assumed we were waiting to have the MRI done. At one point they told us it would be around 20 mins, so we waited. At 6:48pm they came in and said Carol was going down to have a CT scan to which both of us said "I thought she was having an MRI done?" They said no, we are going to do a CT scan then the MRI will come later. Tara had said to me that they would probably take all thier own imaging so it's done wih thier equipment and technicians. They are the pros so we complied and off she went for the CT scan.

It's 8:50pm now, Carol is a bit anxoius and still waiting to have the MRI done. She is still having trouble getting words out and her face looks a bit off. They gave her an Ativan to calm her down while we wait for the MRI. Only a few minutes passed and she finally closed her eyes and fell asleep. I think it was about another hour or so when they finally came to take her down for the MRI. At this point I stepped out and went to our car in the parking garage and had a good cry. I called my brother Rick and filled him in, waited awhile and then went back in. I went to the Urgent care area where she had been and there was another person in her bay. I questioned a nurse where she was, she told me she should be getting back soon. I asked could she tell me where Carol is and she tapped on the computer a bit and then said well she is in the hallway !

That was a bit unnerving.. so I waited in chair at the entrance of the unit so I could spot her when they brought her back. I think it was another hour before she showed up. When they wheeled her in I followed as the attendant headed towards the bay she was in just to be shocked like I was to see someone else was now occupying the space. At this point she became truly a hallway patient.

Finally at 11:50pm she was taken up to the 10th floor of the White building and officially checked in to room 1036B.

Things were quiet now but we had no more info than we had when we got there. I did feel she was in good hands and that everything that can be done was being done. We were told that in the morning there would be a team we would meet and things would progress from there. I was burnt out, she was comfortable so I decided to shoot home and see if I could get some sleep.

First Morning at MGH

August 9, 2011

Got into the hospital around 10am. The first team in was from neurology.was a group of about 4 or 5. They were all young,smart,compasionate people. The one doing most of the talking was very good at explaining things. They discussed possible lung biopsy and additional tests to see if there might be any more satelite sites in the brain. They want to determine what type of cancer is in the lung because that drives what type of chemo will be given. Pretty much a long drawn out morning sitting and waiting.

Early afternoon got a visit from Elizabeth Stover from medical oncology she is the fellow of the medical oncology team under direction of Dr Heist the attending.

She discussed additional testing and possible biopsy.

We got the hierarchy of the doctors, at the top is the Attending then comes the Fellow (the worker bee) then the Resident (senior out of med school) then the Intern (1st yr out of med school) then the Med Student. Nice to know who's who.

The primary medical team consists of a Neurology Team, Radiation Team and Medical

Oncology Team (Chemo).

5:15pm

Got a visit from the Neuro Oncology. The attending neurologist Dr. Jorg Dietrich and Dr. Taylor. Said there was a spot in the right lung and a small spot in the brain with swelling. Swelling should reduce with meds dexamethasone for swelling and keppra for anti seizure. Told us the spot on the brain is in a tricky location on top of the speech center and fine motor skills. The neuro surgery team will decide if the spot on the brain can be safely biopsied if not then a lung biopsy will be done and the brain will be treated with radiation.

Talked about having a CT/MRI on the lower body and said the neuro surgery team may be in later tonight to asses and discuss options.

6:30pm

Ganesh Shankar neurosurgeon resident came in to talk.

Reconfirms that “brain thing” is from another site. That it’s in a tricky location and they will work with medical oncology and thoracic teams to determine additional treatments and possible biopsy site.

7:30pm

Visit from Amy Comander, attending from medical oncology team. Took the whole story again. Discussed biopsy said most likely it will be a bronchoscopy (down trachea to lung). Told us if it is lung cancer there are many treatments available

Day 2 in MGH

August 10, 2011

11:00am

Visit from Samantha Block social worker. She reminded me of Kristen, very pretty young woman with such a sweet voice and a lot of compassion. She talked to us about everything that is available to us and we talked about how we were feeling. She assured us we were in good hands.

Radiation oncology was in. Dr Cheney (resident) told us that the diaphragm scan didn't show anything additional. Said they may want to do a PET and/or bone scan.

Discussed brain radiation treatment.

1:15pm

Christina Kim/ NP was in. She was from palliative care service. Told us they are experts in symptom management, emotional, physical etc. They can help while living with cancer and make it less scary. Can help the patient feel well every day.

Dr Mary Rice (fellow) works with Dr. Colleen Channick (attending) in to talk.

Interventional pulmonology wants to do an ultrasound guided biopsy on Monday.

Need to be off aspirin for 7 days. Carol was on a low dose aspirin.

Dr Allegretti in said a bone scan may be done tomorrow (Thursday) instead of PET scan

Gave Carol an albuterol treatment for possible emphysema. Discussed meeting with smoking cessation group.

Intervention Pulmonary team member Matt Kinsey (fellow) – will be back.

Dr Amy Comander – social visit said she may not be in again and looks like no need for PET scan at this time.

Floor attending? Will be back after 6pm, possible release tomorrow (Thursday).

Hospital tried to give Carol Bactrim (antibiotic) she insisted she's allergic to it and refused to take it. Funny thing, she couldn't get that name right every time it was brought up. She kept saying Bacitracin! She was adamant that it was the one that made her feel real yucky once before. She's been on it since leaving the hospital with no apparent side effects! Too funny.

5:00pm

Dr Matt Kinsey (fellow) Interventional Pulmonary

Explained that the mass is on the right side lung, they see something funny near/on heart, nodules in center along airways.

Explained what to expect in the operating room when the bronchoscopy is done for biopsy and what to expect after.

5:35pm

Dr Elizabeth Stover (medical oncology) checking in

6:40pm

Floor attending was in discussed if need exists for Carol to stay in hospital once the bone scan is done.

Day 3 in MGH

August 11, 2011

11:00am

I just got to Carol's room and they were taking her down for the bone scan she told me they were still trying to give her Bactrim.

2:40pm

We were given details for the appointment with Dr Choi at 9am Tues Aug 16th for fitting of head mask and simulation for whole head radiation treatment.

Another appointment with Dr Heist set for thurs 9am after biopsy is done.

Another appointment set for Dr Dietrich (brain doctor) way down the road on Oct 7th in

Yawkey building after head radiation is complete.

Discharged from hospital later that afternoon.

Back at home

August 12, 2011

Got a call this morning from MGH checking in and explaining what to expect for the biopsy at the same day surgical unit. Dr Kinsey and Dr Channick will be there.

11:29am

Got another call from Samantha (social worker) we met while in her room at MGH, told us if we want we can contact the Social Worker Outpatient Clinic. Samantha only handles patients on the floor.

Quick trip to Cape Cod

August 14, 2011

Carol and I took a drive down to the cottage at the cape to see Kristen and friends.

The Biopsy

August 15, 2011

Got up at 4:30am to get ready to go into MGH for 6am appointment for the bronchoscopy/biopsy. Was a long morning waiting around, she didn't get out till noon time. They had told us there would be a pathology team present while the procedure was done to make sure they get the correct tissue samples and that they sometimes can

give preliminary findings.

No such information was afforded to us so the waiting continues....hopefully we will get details when we have the thurs appt with Dr Heist.

Radiation Mask Fitting/Simulation

August 16, 2011

Met nurse Jayne she's awesome. Met Dr Choi and last year med student Jae. Dr Choi explained the whole process. He told us Carol was eligible for clinical trial treatments when the lung cancer is treated.

Dr Choi stated "The goal is to get rid of the cancer".

Carol did well with the making of "the mask". It was a very open (1/2 in square openings) fabric material they lay over the face and down to the table, then they set it like plaster and becomes stiff and hard. It becomes a device to hold the head steady in position and a means for alignment of the radiation beam.

First Rad Treatment

August 17, 2011

Had appointment for the first radiation treatment at 9:40am at the Cox building.

Once Carol was checked in everything went quick. I was able to accompany her right up to when they administered the treatment. Carol was ok with it all, she even made a joke about the mask, making reference to the famous Boston hockey goalie (Gerry Cheevers) to which the two young men and woman techs had no clue !!!!

The treatment only takes minutes and is painless.

We set up for valet parking at the Cox building where they do the radiation, it makes for easy in, easy out.

After this first visit you get a card with a bar code on it so next time you don't even have to deal with the front desk, just walk in, swipe your card and the next thing you know is they are calling your name on time if not before.

The whole process is made to be easy and relaxed on the patients.

Meeting With Medical Oncology

August 17, 2011

Had meeting with the Medical Oncology team of Dr Heist (Attending) and Dr Stover (Fellow).

As noted by my guardian angel Nancy (Carol's sister)

Dr Stover reviewed meds and current status. Dr Heist said it was ok to go back on baby aspirin. Told us the diagnosis, mass in right lung, central nodes on right (small one left), mass in brain.

Full pathology of biopsy was not complete as of yet, however Dr Heist presented as Cancer Stage 4 since it has metastasized to the brain.

Said its always stage 4 when it has metastasized from the primary site, stage 4 is not cured but treated to promote quality of life.

Lung cancer would become 3A if the brain cleared and tests show no advancement.

Stage 4 = months to years

Carol is atypical stage 4 since there is only one metatastic site,the brain, and is very healthy otherwise = produce good results.

TREATMENT FOR LUNG

Decision will be made after the head radiation is complete. approx 1 month. After brain

treatment ends there will be a full PET/CT scan to restage the cancer and address lung treatment based on new info. If it's stage 3A then aggressive chemo/radiation, If there is more disease then chemo only treatment may be recommended.

Dr Heist stated "With treatment we can give you a good quality of life"

Chemo/radiation would intail radiation 1x/day for 5-7 weeks along with chemo 1x/wk initially with longer/stronger chemo after intitial period.

Chemo only would be 1x/3wks (long day).

They changed Bactrim dosing to 3x/wk. Bactrim / Dexamethasone will continue for entire brain treatment.

They told us radiation anticipated to end Sept 8th, said around the 16,17,18th the PET/CT would be done. PET/CT scheduled for Sept 16th 10AM. Follow up with Dr Heist scheduled for Sept 21st.

4th Rad Treatment

August 21, 2011

Carol had her 4th radiation to head today. Met with Dr Choi / Dr Cheny.

Said it's possible to reduce dexamethasone to 3x/day by weeks end.

Reducing could result in return of symptoms.

Told us there would be a waiting 10-12 days before SRS (Stereotactic Radiation Surgery) treatment would be done. (15th and final head treatment)

http://www.massgeneral.org/cancer/services/radiation_oncology.aspx

Appointment with Dr Willers scheduled for Sept 8th, he will be doing the SRS

Dr.Willers

<http://www.massgeneral.org/cancer/doctors/doctor.aspx?ID=17147>">WILLERS

9th Rad - Monday Meeting w/ Dr Choi

August 29, 2011

Pretty much quick visit, Progress continues (slowly) Thrush still persists, refilled Nystatin. Gave Rx for Ativan refill. Discussed upcoming SRS. Confirmed to change Dexamethasone to 3x/day.

Carol is feeling really fatigued and ravenous for freeze pops and everything else she can find, especially the York Peppermint Patties.

Hair loss started yesterday, we took a look in MGH's "Images Boutique" while there today.

<http://www.massgeneral.org/services/imagesboutique.aspx>

Thanks to all who reach out it's truly a godsend.

Love you all

11th radiation treatment

August 31, 2011

Carol's sisters Nancy and Mary took her in to MGH for her appointment today. After that they visited the Images Boutique at the Yawkey center so Carol could get a wig and other assorted sundries....

I saw her early afternoon, I waited around here at the house after lunch so I could see her before going back to work. When they pulled in the driveway and Carol got out she was wearing her new prosthesis and I thought to myself wow...who's that babe they

brought home ! =)

She was really tired and fatigued from all the walking so she settled in to her spot on the couch and drifted to sleep.

Good spirits all in all...just tired

I got her to go out for dinner with our friends the Simeone's at the Rose Garden, we had a great time eating,drinking (couple mai thais' and I was good!) and good conversation. She just wants to get through the next two days then she has the long weekend to herself. Maybe we'll go up to UNH to see Kristen??? Kristen called me at dinner she's doing fine,in good spirits and got a job working for the athletic dept....awesome !

Tough Couple of Days

September 2, 2011

Carol had her 13th radiation treatment this morning. I took her in myself to be with her. We visited the Images Boutique again and she got some more nice soft hats. The wig looks great (she wore it in today) but it isn't as comfy on her bare head as the hats.

By the end of the week she is just fatigued out and spends most of her day sleeping, it sucks I have to wake her up to take her meds.

If people are looking to call her your best bet is around
6am/12pm/2pm/10pm/11:30pm-12am.

Anyone got some dinner recipes for non spicy,not hot(heat) / mushy foods??? mashed potatoes are getting old. Her mouth is so sore it's painful to eat.

caringforcarol@giombetti.net

She is hopeful that she will feel a bit better having the long weekend ahead with no appointments. She wants to go up to UNH on Sunday to see Kristen,we have a dorm fridge for her we want to deliver as well.

Thanks to everyone for your outpouring of support !

Visited Kristen at UNH

September 4, 2011

We drove up to New Hampshire this morning to visit Kristen at her dorm. We brought along a dorm size fridge with us for her room. The one they had was really small. We got there around Noon, Carol slept most of the way up. We did make one stop and she was able to eat a little of chicken wrap sandwich.

I took a few pictures of her and Kristen

<http://smu.gs/pnRtxD>

It was a lot for her, she is just so tired and fatigued and the sore mouth doesn't help. Got home and it's beddy bye time for her ! I'll see her at 10pm for meds.

University of New Hampshire is a very nice campus, feels sooo...homey.

Visit From our Guardian Angel

September 5, 2011

Morning came,
if I had let her Carol would have spent all day in bed.
I have been trying to find a balance between pushing hard and totally backing off. But it all worked out as it may, with a visit from our guardian angel Nancy. She brought along some angels in training Mike and Rachael and then it just so happened sis Mary and hubby Steve dropped in. So I prodded and pushed and Carol joined us all in the living room for a nice afternoon of family togetherness. Nancy helped me with some paperwork,,just having another set of eyes was very helpful.

My brother Bob and wife Anne stopped by after everyone else had left, Carol had retired

back up to bed at that point. Anne made us some soft cookies and soup I will try and get Carol to eat tomorrow.

Carol returns for radiation treatment in the morning, this will be the last regular whole head one (14th), then there will be one more done as a SRS treatment (Stereotactic Radiation Surgery) directly on the brain tumor. After that there's some waiting and more tests MRI, PET etc. and then we meet with Dr Heist (lung cancer specialist) to discuss current status and paths forward for lung treatment. I'm hoping tomorrow they can do something more for her sore mouth.

Wednesday - Hump Day

September 7, 2011

So Carol had the last regular whole head radiation treatment yesterday. When we first arrived we told Jayne the nurse that Carol's mouth was killing her and could we do something about it. She said absolutely and got Dr Choi to come in and take a look. He prescribed Fluconazole (triazole antifungal drug) and a "triple mix" (Ilicocane/Q-Dry/maalox) solution to replace the Nystatin to swish and swallow. They discussed the upcoming weeks appointments which I had slightly wrong in the previous post I think. Tomorrow Thursday the 8th we meet with Dr Willers (who will be performing the SRS treatment on the brain tumor) for a preliminary sit down. Then on Wednesday the 14th she gets a MRI. On Friday the 16th she gets a PET/CT scan (to see what the big picture looks like). Then on Monday the 19th we meet with Dr Choi and Dr Cheney to discuss treatment planning and simulation for the SRS, during this visit we should get a date that the treatment will be done. On Wednesday the 21st we have an appointment with Dr Heist and Dr Stover (the lung cancer specialists) where I believe we will get information on the current status (re-staging etc) and path forward for treatment of the lung.

After yesterday's treatment, it being the last one, Carol was given "the mask" to take home. The new meds for the mouth thrush seem to be helping. Carol had scrambled eggs for breakfast and tonight I made her some broiled haddock and a baked potato which she was able to eat some of and sherbet for dessert. They also cut her Dexamethasone (steroid) to 2x/day. She has been much more awake through yesterday afternoon and today.

Dr Heist - <http://www.massgeneral.org/doctors/doctor.aspx?id=17268>

Dr Choi - <http://www.massgeneral.org/doctors/doctor.aspx?id=16462>

Change of Plan

September 8, 2011

Took Carol in this afternoon to see Dr.s' Cheney and Willers. Dr Willers is the one who will be performing the SRS treatment. Dr Willers said he wants to wait before doing the procedure, that the longer we wait the better. Typically he likes 1 - 3 months to insure that the tumor has shrunk from the whole head treatment. I heard both gentlemen say they want the best chance to achieve the goal which is to, in my own words, "kick this thing in the ass".These guys are really positive in their abilities.

So now (SRS) has been rescheduled out to beyond Oct 7th (when she gets her MRI) however the "whole treatment" moves forward. Carol has 7 days without appointments, not until Friday the 16th is her next one for the PET/CT scan.

Then the next Monday the 19th we meet with Dr.s' Choi and Cheney et al.to discuss radiation protocol on the lung. (I had this confused,I thought this was for the SRS).

On Wednesday we have an appointment with Dr.s' Heist and Stover and they will start talking about moving forward on their specialty, the chemo.

"Keep hold of instruction, do not let go; guard her, for she is your life" (4.13)

The "Mask" >>>> <http://smu.gs/nSKqgc>

Monday - A New Week

September 12, 2011

Well, Carol has had some time home now. We got out the other evening and had dinner over Mel and Dan's with Ed and Karen attending as well (she's following in her mom's footsteps as everything was great,including the company). Carol's mouth seems to be on the mend with the new meds she is braving a little more substantial foods now, however the fatigue still persists and her legs just have no strength in them. She is struggling on

stairs and even collapsed twice (I was there to catch her). So it's no stairs alone right now. I called nurse Jayne today about it and she was concerned but said it's typical with the double whammy of radiation and heavy steroids. She called Dr Cheney who called me back to calm me down and explained what she is going through, it's a tough road but I know she will rise to the occasion. One day at a time.....

Love to all from Carol and I, it really is all about family ! and that goes for all the extended family as well ! Thank You

One Day At A Time

September 15, 2011

Well today is better than yesterday, Carol has a little more energy, her mouth is feeling a bit better, had a KFC chicken bowl for lunch which sis Nancy was so kind to deliver. The M&M fairy came by yesterday and left a present in the mailbox !

Tomorrow she has an appointment in the morning for the PET scan. I will say a prayer that the results will bring us positive news as we move forward in her treatment.

PET Scan Pike Friday

September 16, 2011

So Pike traffic sucked on the way in to MGH this morning just adding to anxiety. After checking in waited a while but eventually got moving. First Carol had a radioactive marker injection. The marker is mixed with sugars that the cancer cells consume more than others giving (contrast) to the imaging. Had to sit in the waiting room about forty minutes while at the same time having to drink up a big slug of Barium Sulfate.

While Carol was drinking and waiting my cell phone rang and it was Dr Choi's office asking if Carol could make a 2:15 appointment to get a pulmonary function test done, that is was important to have it done before we meet on Monday and that it was

needed for Carol to be in the trial. At 10:52 Carol was taken down for imaging, they told us it would be about thirty or forty minutes.

Got out of imaging and had some time so we took a walk, or should I say I walked, Carol rode the wheelchair and we went over to the Yawkey building up to the outdoor healing garden on the seventh floor. It has a nice view of Boston harbor. We went back to the White building cafe and had some lunch and from there it was off to the Cox building second floor for the pulmonary function test. Got home around 4:00 she was pretty tired out by this time and konked out on the couch. I took the time and went food shopping and got some nice fish for dinner. Carol seemed to eat better and finished her plate along with the chocolate milkshake and even had a bowl of fruit (cut melons) for dessert.

Today really tuckered her out but she did a great job, she deserves her rest now, tomorrow is another day.

Rough Weekend

September 18, 2011

Last few days has been a challenge for Carol. She is just so tired and has no leg strength. Needs help getting around especially on stairs. On a good note her mouth is clearing up, however she lost appetite last day or so.

We had visitors this afternoon and I in the evening, that helped a lot.

Tomorrow it's a 2'Oclock and a 3'Oclock appt with the radiation oncology people to plan out the rad end of treatment on the lung, hoping maybe they give us something good about the PET scan. This is weighing heavy on her mind.....

We have an appt with Dr Heist and the medical oncology group on Wednesday. I assume if not tomorrow then at this meeting we get the PET results and talk about it.

Prayers Answered

September 19, 2011

Met with Doctors Choi and Cheney this morning. We were supposed to get all the way through up to and including the "planning / simulation" for radiation treatment of the chest. Carol was so fatigued and feeling crappy that they decided to postpone it till Wednesday. We already had an appointment on that day with doctors Heist and Stover so they hope to work in the planning / simulation as well.

They did give us the results of the PET scan and that was good news, there is no change/advancement of the disease.

Carol signed the document for being part of the clinical trial study that will allow the latest treatment to happen. It is an aggressive radiation/chemo at the same time therapy. It sounded like that would not start for 10-12 days after the planning is done. I think we will get further information when we meet with Dr Heist on Wednesday.

Long Day

September 21, 2011

Today was a very long day for Carol. We woke at 6AM to get ready to leave by 7:30-7:45. Our Angel (Nancy) was with us today. As expected we hit traffic on the pike that delayed us but somehow managed to walk into the first appointment to the minute at 9:15. First order of business was lab work then on to meeting with Dr Heist and Dr Stover the medical oncology team. We discussed all the options including the clinical trial. They shared the PET scan results with us, that there was no change or advancement and that they actually saw a decrease in size of the mass. They weren't sure why that (size change) was but said it's possibly due to the steroids, prayers etc. They told us the fatigue and tiredness was not unusual for someone who has had whole head brain radiation. Carol was a bit dehydrated and suggested we have her take an IV for fluids which we scheduled for after the next appointment with Dr Choi and Dr Cheney.

Went to the Cox building for the radiation simulation and met with Nurse Jayne and Drs Choi and Cheney. They were pleased that Carol showed some improvement over the last visit. Her feeling pukey symptoms subsided after restarting the Dexamethasone. They said they would like her to stay at 2x/day for about a week before beginning to taper it off again more slowly than last time. They said they are very optimistic moving forward with the trial treatment. It won't be easy, as Dr Choi put it, "to catch the tiger by the tail

you will get a scratch" Carol was then taken in for the simulation, a 4D CT scan that lets them map out the treatment area in detail while she's breathing. I hadn't thought about that, but if you think about it, it's a moving target as the lungs expand and contract. So the 4D CT maps out the whole thing while breathing. She got 4 itsy bitty tattoos for markings.

They suggested trying to find something else besides water and coffee coolatas to drink, something like gatorade and such. Said the coolatas wern't that good because they actually make you expel water. They set up the treatment plan which will start beginning of October. They would like to see Carol recover some more from the fatigue etc before starting.

Left the Cox building and headed back over to Yawkey 7th floor for carol to get IV fluids. That was to take 2 hours, so our Angel and I went and got something to eat and hang out a while.

Got home around 4pm. My brother Rick stopped in and spent a couple hours with us.

One day at a time.....

A Rough Stretch

September 25, 2011

It's been hard the past few days. I think some depression has set in on top of the feeling tired, fatigued and generally shitty otherwise she is eating, drinking and taking her meds. We have appointments on Tuesday at 9AM,10AM and 11:30AM at which my guardian angel will be present with us. Hopefully some good things will transpire from there.

Love to all !

Thank you !

Put The Brakes On Treatment / Mealtrain Has Left The Station

September 28, 2011

Went in to MGH Tuesday morning for appointments. We left the house early once again to make it in for the first one at 9AM. When I checked her in at the desk they looked at me cross eyed and said your appointment is at 10AM. I told them I was called a couple days earlier and was told I had a nine o' clock added on top of the ten and eleven thirty. Well I guess things got a little messed up in their scheduling so we waited around till almost 10:30 before we were called in to get started.

We met with doctors Heist and Stover to start. Carol voiced her wishes and feelings to them to which they were taken aback. Carol, because of feeling shitty and depressed was fixated on stopping all treatment and just moving ahead with palliative care only. Dr Heist said they needed to do a better job treating the symptoms. What Carol was asking for (not written here) was not an option and was now told so by the doctors. After we talked a while they left and consulted Dr Pirl (pshyc) and NP Connie Dahlin from palliative. Dr Pirl and Connie then came in, sat with us, and we all talked a while. Dr Pirl did his evaluation and agreed that Carol was suffering from some depression and suggested she try some meds to help get her back in a good place both physically and mentally before proceeding with any more cancer treatment. Ritalin was prescribed to stimulate and Celexa for depression. He said the Ritalin may start to have some effect in a couple days to stimulate more energy and focus however the Celexa will take a week or two to really kick in.

So now it's get Carol feeling better before we continue (if she decides to) with the plan and track she was on.

We got home mid afternoon and she was a bit better in spirit. She now heard from the doctors what Nancy and I had been telling her.

I got her into bed earlier than normal and with some Ativan she was out for the night.

Wednesday morning (today) came and I woke Carol at 6AM. She was feeling a bit better than yesterday. I let her hang in bed for some time as the new medicine needed to be given an hour after the first round at 6AM. I made her some pancakes which she ate up along with an Ensure shake. She had a long day today with visitors stopping in which I think was a really good thing. Interaction instead of isolation. My brother Ed has instigated putting together a calendar on the MealTrain website for us where people can help out by making dinner for us in a coordinated manner. Thanks Ed ! The MealTrain left the station tonight with Dianne Clue at the throttle. She made us a wonderful beef stew and fresh home made bread, thanks Dee.

One day at a time ...

What A Difference A Day Makes

September 30, 2011

Well here it is....Friday. I took the day off today to be with Carol and see if I could get her out of the house. Started the day with some "real" home made egg/sausage/ham sandwiches from Sunny Side.Carol is definitely more alert and perky today than yesterday it's just that lingering weakness in the legs that's a bitch. Anyway I took her out for a drive, we went to Hopkinton State Park and walked around a bit. Just getting out in the fresh air and sunshine felt good. From there we went to Target in Milford to grab a couple things then on the way back to Ashland stopped for a Coffee Coolatta. From there we went and visited my mom Rita who needed a new phone installed in the kitchen. Spent some time there in good conversation.

Were back home now and just hang'n out till the MealTrain arrives. Tomorrow were planning to possibly visit the Hopedale Oktoberfest in the morning where brother in law Steve fly's model airplanes with the Millis Model Aircraft Club and then definitely driving up to UNH in the afternoon. I got a hotel room right downtown Durham for the night (Sat) and we will see Kristen on Sunday and drive back home.

No appointments till next Wednesday when we meet with doctors Heist,Stover and NP Connie for a follow up. Dr Cheney called me today to check in on us, he's been great ! We will most likely meet with him and Dr Choi on Thursday before Carol has her MRI on the head to see how the brain thingy is doing.

That's about it for now, big thank you to everyone who is supporting us through this difficult time, Love you all ! =)

Took some photos at the State Park.... <http://smu.gs/oO78Ry>

The Weekend

October 2, 2011

On Saturday we took a drive over to the Hopedale Oktoberfest before later in the day taking off to New Hampshire to see Kristen. Even though it was a crappy day weather-wise it was good to get out and do something. Carol still isn't strong on her legs but she manages and is trying hard to get some strength back. When we got there we hung out at the pond where the Millis Model Aircraft Club was setup doing some demos flying planes. Brother in law Steve was there so we chatted a bit and watched the guys have fun. I wish it was a sunny day so we could have enjoyed more of the event but that's ok we had a nice time anyway. Some photos >>> <http://smu.gs/pAE9IU>

From there we headed on up to UNH late afternoon. We checked in to the Holiday Inn Express just outside downtown Durham around 4 or 5 PM. It was a nice room in a small venue kind of atmosphere. I called Kristen and we picked her up at her dorm and took her over to Market Basket to get some things she wanted and we picked up some essentials for ourselves for the room overnight. Carol was kinda pooped after the long day so I brought her back to the room with Kristen, we hung out a while and then Kristen and I drove back to the campus and grabbed some dinner at the Holloway dining common. Kristen recommended the stir fry so that's what we got and it was really good. We had a nice talk and spent some time together before I walked her back to her dorm and headed back to the hotel.

This morning (Sun) we went back to the campus and picked up Kristen. We took a trip up to the Trading Post in Kittery Maine on Rte 1 where she was able to find a nice pair of winter boots. Yeah winter ! right around the corner...the weeks are just flying by. We took the girl back to her dorm and dropped her off and Carol and I headed back home.

Kristen is looking forward to coming home next (long) weekend and sleeping in her own bed for a couple nights. She has to work Saturday so she can't leave till later in the day but can spend Sunday and Monday.

Carol has been pretty active these past few days. Visits from family and friends keep her busy and her spirits are up.

Tomorrow is another day...unfortunately for me it's a working Monday ! =)

Mid-Week Update

October 5, 2011

Just got home from MGH ~ 4pm. Left this morning around 8:30AM and hit the usual pike

traffic. Got into the hospital with plenty of time for the first appointment at 10:30. Sat around the waiting room for a quite a while being a bit early didn't help but rather be early than late. I guess I knew things were not going to be quite on schedule when the big guy over the other side of the room fell on the floor in pain ! I heard at least two others mention they were waiting for Dr Heist as well, oh well. Dr Stover did eventually come out to the waiting room to see us. She was pleasantly surprised to see Carol was doing so much better than before. She decided we should reschedule their appointment to next Wednesday so we did. At that point we shuffled on up to the 9th floor to see Dr Pirl (physc) for the twelve o clock. He was also quite surprised to see Carol was doing so good compared to last week. He said things appear to be working so no change just keep doing what were doing. After that we went down to the lobby and grabbed some lunch and waited a while before returning to the 7th floor to see Connie (palliative) for the two o clock. They were still a bit behind schedule and by now Carol was getting tired with all the sitting around so they brought her back in to the short stay room where she was able to catch a few winks in a nice recliner chair. When Connie came in we had both nodded off, she got a chuckle out of it and then was also surprised to see Carol was in such a better state, she was pleased and said everything is going good and to continue doing what were doing. So all in all not much to report other than Carol is doing ok and we will see these doctors again in the week(s) to come. She still has appointments this Friday with doctors Cheney and Choi, Dr Deitrich and a MRI on the head at 3:30pm.

Physical Therapist Kelly came over Monday to say hello and do an assessment. She will be coming twice a week for 4 weeks she said.

The journey continues..... hand in hand

Taking it Day by Day

October 9, 2011

It's officially Monday morning as I write this at 12:06. The weekend has come to an end for some like me who has to work. Eric went up to UNH on Saturday to bring Kristen home to spend some time. It was a short visit as she was called to work on Monday. I drove her back this (Sun) afternoon.

During the day I was able to get Carol out for an excursion. We drove over to Plains Park in Milford to watch the model plane show that Millis Model Aircraft Club hosts each year. The big boys with their really expensive toys come out to play and they draw quite a crowd. I'm not sure if it was just the overwhelming fatigue or the lack of interest but

Carol could only take it for so long. We waited long enough to see one of the big planes fly but that was about it and left before he even finished his flight.

Carol had her MRI done on Friday after meeting with Dr Choi and Dr Cheney. Matt (Dr Cheney) informed us that he has to leave us as he is a resident and must now change departments. He told us he will be watching and we can call him anytime. Dr Choi was happy to see Carol doing so much better than before. Carol will be having to get the 4D CT scan done again now that weeks have passed after the 1st one was done. We will be meeting doctors Heist, Stover, Connie and Choi this coming Wednesday where I assume we will be afforded the results from the MRI. Hopefully the MRI shows that the tumor has shrunk as planned to help pave the way to further progress. The appointment with Dr Deitrich (neurologist) was cancelled and will be rescheduled, as it was made way back when Carol was discharged from the hospital and was no longer relevant timing wise.

We'll see what this week brings, hopefully continuing good news.

Some photos of the MMAC Air Show >>> <http://smu.gs/nZi2vF>

MRI Results

October 12, 2011

First appointment today was with Connie from palliative. She said Carol was doing much better than last week and discussed moving forward. She stressed the fact that now is the time for Carol to make known her wishes to the palliative care people while she is in a good place. Carol inquired about the MRI results to which she (Connie) deferred to Dr Heist.

Met with Dr Stover next who also said Carol looked great and seemed to be in good spirits. She went over the options again moving forward and said the chemo/rad treatment is still an option and in her opinion is a viable one. Carol will need to make a decision and Dr Stover said it would be best to schedule another meeting next Wednesday to give her time to think it over. Carol asked about the MRI and Dr Stover told us that there was improvement/shrinkage of the brain tumor and that this is very good. She also said that there is a spot on the other side that showed up as a "haziness" in the imaging and deferred further discussion on that point to Dr Heist.

Dr Heist then sat with us and basically went over the same stuff about moving forward. She said Carol was doing great compared to last week and agreed that a meeting next

week would be good to discuss the details moving forward. She spoke to the MRI results a bit more and said the "haziness" will be watched closely, they can't say definitively what it is.

The next appointment was with Dr Choi at 1pm so Carol and I went down to the cafe' in the Yawkey lobby and grabbed some lunch before heading over to the Cox building. Dr Choi sat with us, he introduced the new resident Dr Jen Pretz that took Dr Cheny's place. He explained the MRI results further as he is the one responsible for this part of the treatment. He stated again that the tumor has improved/shrunk and that's a good thing. He said the "haziness" could be the results of a few different things but he suspects it to be Limbic Encephalitis and it may be the cause of Carol's slight struggle with memory/thinking ability and also fatigue which has persisted. He told us that this condition is typically caused by the primary cancer of the lung which has not been treated in any way yet and it typically gets better after the primary site is treated. He stated that Carol may not improve greatly from these symptoms, as they are now, until the lung is treated. He said there *is* a "window" of time to commence treatment and that it's not getting wider. He suggested Carol has the 4D CT scan done as soon as possible as opposed to waiting because after that is done it's a two week minimum wait before treatment can start. Carol was in agreement to add the scan to next Wednesday's appointments after we meet with doctors Heist and Stover.

The MealTrain was running tonight and we had a great dinner thanks to Patty T.

One Day at a Time

A long Week

October 19, 2011

It's been a long week waiting for the next appointment today. Carol continues pretty much at the same level. She sleeps every chance she gets, just feels tired all the time. Her leg strength is the same and continues to struggle on stairs. I took her out over the weekend to Cushing Park in Framingham they have a nice mile of paved walking road. It was a glorious day out sun shining bright. Carol only made it a few hundred yards and wanted to turn back. At least we got out of the house into some fresh air.

Met with Dr Stover and Dr Heist at 11AM. Basically gave Carol a once over and all vitals are fine. She still struggles with short term memory loss and confusion, which the doctors experienced first hand. She acknowledged to moving forward with the trial study

treatment (chemo/rad) and the doctors were supportive of it. All things are still positive despite the Limbic Encephalitis which the doctors agreed should show improvement once the primary site is treated. The schedule on the chemo side has been set up and should commence two weeks from today. That coincides with what Dr Choi had said however I suspect I might get better detail on that when we return next Wednesday to meet Drs Heist and Stover for a further detail chat on the chemo side of things before that starts.

Today we had to kill three hours after the morning appointment. It was noon when we finished that, so we rolled on over to the cafeteria in the White building. That was a mistake, I guess maybe because of the rain everyone within the place decided to eat lunch ! Oh wait...it WAS noon duh! I circled the wagons for a good 10 minutes trying to snag a table but when the second person stole the second table from under my nose before I could get the freak'n wheelchair close enough quick enough to claim it I said F****K this! So we left and went up to the gift shop and poked around a bit. Well there happens to be another little satellite eatery right around the corner from there and there was a table open. We sat and had a good lunch but still had over an hour and a half to wait. We decided to just go to the next appointment and wait there seeing it was right next to where we were. We went down to the Cox and checked in for Carol's 4D-CT scan which was to be at 3PM. It was trying on Carol to wait so long but at about 2:15PM they came out and said let's go. That was a good thing and I accompanied Carol back into the procedure room where I was allowed to stay right up to the "moment". Carol did fine and it was over in short order, all she wanted now was her couch...

Journey continues...

Moving Ahead

October 26, 2011

Met with Connie and Lauren from palliative first today. They did an evaluation and increased Carol's Ritalin to try and improve her energy. She is still always very tired and her cognitive skills are still a struggle. I set up a whiteboard in the living room to put all details of the day for Carol to reference and make it easier for her to keep things straight.

We met with doctors Heist and Stover who had Carol sign the forms to move ahead with chemo treatment. They explained what to expect again and were pleased Carol was ok with moving ahead.

We then went to the new Lunder building to meet with Dr Choi and Dr Pretz (new resident). Carol had to sign their form again because a month has passed since signing the first one. The scheduling is in place and tomorrow we have to go back in at 2pm for the final simulation for the radiation. The treatments will start on Monday at 6:20pm and the first Chemo is scheduled for Wednesday at 11:30am.

I'm hoping we can do something about the six thirty rad treatments so we don't have to wait so long after chemos on Wednesdays.

A dear friend of ours Robin has set up an appointment for Carol to receive acupuncture therapy right here in Ashland on Friday, I'm hoping it has some good effects on her.

Carol and I did get out for a walk the other day, she did well and went further than before with a little prodding. We also got out again going to Rose Garden with Bill and Sue and had a nice dinner. The Mai Tais are really good there ;-)

"Learn from yesterday, live for today, hope for tomorrow." [Albert Einstein](#)

Only in New England

October 31, 2011

It's been trying these past few days but God willing we will get through it. Carol had an acupuncture therapy this past Friday thanks to Robin, I joined them as well and found it quite relaxing as did Carol. I hope to be able to find some time slots that work so she can continue, as this would afford the best positive effect from it.

Only in New England...hmm mm seems I've heard that before ! Enter... latest Nor'easter in October !. We lost power around 1am Sunday morning. I listened to cracking timber on and off in the wee hours and there was one that sounded a bit close. When I finally awoke around 4am the first thing I noticed was the unusual quiet in the house and it felt a bit chilly. I looked at the clock and it was dark and then it hit me the power went out overnight. I was tempted to get up and check things out but it was still dark and decided to stay put until dawn broke so I could move about the house without artificial light.

I don't know exactly what time it was but when I looked out my bedroom window and saw the dawn breaking I felt like I had to go downstairs and see what the day had brought. I walked over to the back door and when I looked out I saw something I didn't expect. Instead of looking out to the porch and beyond I was looking at the top of a maple tree stuffed up against the storm door ! I flipped on the flood lights to get a better look and that's when I saw the extent of the storm's wrath. Two big maples part of a four tree cluster had come down, one laying straight at the house and just short of doing big damage and another hung up on another tree just short of the shed. I let Carol know that there was nothing to do except sit back and relax, I had some hard labor to attend to.

I fired up the generator and got the house warmed up, made some breakfast, got Carol comfortable and waited till a reasonable hour before firing up the chain saw and attending to the matter at hand. With some help from brother Ed and son Eric and an honest day's hard labor we made short work of it. Hope to have some great fires at the pit...

Some photos>>>> <http://smu.gs/u7LkHP>

The day before, on Saturday Carol and I took a drive over to Bernie and Phyls and bought a nice comfy powered recliner, she took a shining to the one at the acupuncturist and I thought it would be a nice change from the couch.

Today was a high anxiety day for her, thinking about the radiation treatment, all day. Her appointment was at 6:20pm. Sister Ann accompanied us in. At first I wasn't sure about the late appt. time but we left the house around 4:30 and sailed right into Boston. I wish they all could be this easy !

Carol got through it ok and the schedule for radiation is in place. She will receive treatments daily some at 5:45p some at 6:20p excluding weekends and holidays until Dec 22.

Chemo starts this Wednesday at 11:30a as well and continues once a week for seven weeks.

"To know the road ahead, ask those coming back" Chinese proverb

First Chemo / Third Rad

November 3, 2011

Carol struggles still with memory and cognitive/perception skills and also continues to be very fatigued. She has now had 3 radiation treatments to the chest and had her first chemo yesterday. She did very well at chemo yesterday and rested/slept through it all listening to an Ipod I brought with noise canceling head phones from Bose. A little Carole King and such. My niece Rachael (sister Nancy's girl) accompanied me the whole day through chemo then radiation. She's a nurse at St Vincents in Worcester currently working an Oncology floor dealing with chemo, it just so happens.

Tomorrow we start early with a 9AM with Dr Pirl. See if we can get Carol a little less depressed. I hope to get the radiation treatment slipped in after that meeting so I don't have to wait too long.

"That which is bitter to endure may be sweet to remember."
Thomas Fuller

Ups and Downs / Week 2

November 9, 2011

Sister Nancy is taking Carol in for her appointments today. She has one with Dr Pirl to start the day at 10am, then Dr Heist/Dr Stover, then infusion at 1pm. After that it's off to see J.C. at the Cox radiation center for treatment # 8.

Dr Pirl added Zyprexa to Carol's meds and she seems to be doing better. There has been a pep in her step as of late and is doing more around the house.

She hasn't had any real added side effects as of today, I hope that continues.

Were reaching 14 weeks into this now and I can't believe the holidays are around the corner. I know what I want for Christmas ! =)

"In the midst of difficulty lies opportunity."
-- Albert Einstein

Long Weekend / Long Ride

November 10, 2011

Sis Ann took Carol in today for her 5:30 treatment. I thought they were a little late getting home tonight and I found out why. They said the traffic was absolutely horrendous both going in and out. Ann said at one point they were stuck in gridlock going in right next to the hospital on the road that leads up to Blossom street where the Cox entrance is about a block away and that Carol actually got out and walked the rest of the way because they were running so late.

After settling in a while back home, around a little after nine o'clock, we had the pleasure of welcoming home Kristen from UNH. We hope to have a nice family weekend together. The weather looks to be cooperative and maybe we can get out and do something in the nice sunshine.

Carol seems to be doing ok with treatments thus far, nothing adverse as far as nausea and such and I hope it's a good sign for the road ahead. Dr Choi had mentioned this past Monday that it's coming up on six weeks (in 2 more) at which time another MRI on the head will be done to assess progress.

Every day is a gift,embrace it with Love.....

Tomorrow MRI

November 20, 2011

Carol has been taking treatment well,she has a little more strength in her legs and has been walking more at her appointments. Tomorrow is a milestone with the MRI being done at 1:45pm at MGH West Imaging in Waltham, we hope to hear good news in that respect. After that treatments continue as scheduled out to Dec 22.

Note to Self ...

November 21, 2011

Fall in New England, Mmmmmmm. There's something about that air when you first step outside in the morning isn't there? Smells like... a new day every day is a "new day". Carol and I headed into MGH West Imaging in Waltham around 12:30, it was an easy commute up and right off 128. Carol wanted her usual Ativan to chill out before the MRI but today decided to ask me for two. <note to self> I decided eh what the hell so I complied and gave her two. Needless to say she made it through the scan with no problem ! *end*<note to self><don't do that again !>. By the time we hit MGH downtown for the weekly visit with Dr Choi, before rad treatment, she was well sedated.

Dr Choi and Dr Pretz were able to view the images by the time we got there, talk about the information age ! We were told that the Limbic Encephalitis has decreased and will hopefully continue to do so. The tumor has changed a little but Dr Choi said he believes that's because the Edema that once surrounded it has completely cleared which removes lot's of pressures in lot's of places, allows the tumor to shift. He said they would start to plan for the SRS as originally planned now that the Limbic is subsiding. All in all everything is positive.

Next stop on the tour was to the COX building to see Carol's friend J.C. Those are his actual initials on his badge, I've yet to ask him what they stand for. I think I'll just let them stand for what my mind tells me. He's the guy to know in the radiation oncology! By the time Carol was done with this one she was clearly showing signs that I probably shouldn't have given her that second Ativan ! see >note to self<.

The ride home was very interesting at one point I think she really was hallucinating, she seemed ok with it so we had interesting conversation.

After that she decided, all of a sudden, she was hungry ! Hungry for a that perfect Roast Beef Sandwich. We decided to make a stop on the way home so we pulled in to Kelley's Roast Beef up at Jordan's Furniture and had supper. She finally found that taste she was searching for I think, unfortunately Nick's roast beef sub just didn't "do the trick" just the day before... Hmmm... somebody's got an appetite !

The MRI was just for the head check, the primary chest treatment will continue as planned up to Dec 22. It will be some time after this treatment ends before a CT/PET scan will be done to assess progress.

Pick a Star and Set Course

Christmas

December 5, 2011

Hard to believe the Christmas season is upon us. Seems like I had just left on vacation. We had a nice Thanksgiving with family, this year at Dave and Sue's, and Carol was really alert and had quite an appetite. We watched a quick video I made of Thanksgivings ago with a little special clip at the end. That clip can be seen here <http://giombetti.net/thanx.html>

I was able to get Carol out after that on an excursion to her sister Ann's on the annual ravioli making undertaking... pics here

<http://smu.gs/urkOzh>

Carol pretty much played couch potato while the gang had fun in the kitchen making a mess. They did move along pretty good and had 50 made in no time, can't wait to eat em on Christmas!

Treatments continue, she is handling them well hasn't relied on any medicine for nausea and has had a little more energy although gets tired out quickly. Appetite is back to eating everything in sight =)

Those pesky steroids !

Three more infusions to go (the next 3 Wednesdays) and 12 more radiation visits (weekdays till the 21st) However this past week we met with Dr Willers who will be doing the SRS procedure. He said it's time to get that through the planning and scheduled for treatment. So Carol has appointments first on the 15th for planning and then on the 22nd for the treatment. That will conclude the whole treatment plan as scheduled.

After meeting with Dr Choi yesterday he wants Carol to get a CT scan. The machines were booked all week except for one opening tomorrow at 8:45am so we took it. I assume this is to see what's going on in the chest thus far.

Got the tree out tonight, have to make it Christmas-sy around here...

Hope Santa is good to us all this year !

"Christmas isn't a season. It's a feeling."

Edna Ferber

Stay the Course

December 14, 2011

Wow December fourteenth already, Christmas just around the corner !

Giombetti Christmas party is this Saturday and Carol and I are planning to attend. As I think about the party I can't help remembering the gatherings we had growing up at uncle Aldo's. We were the kids then and now new generations bless us with the laughter of their children and the joy and fun continue.

Kristen will be coming home Saturday morning after she finishes her last final. She is bringing her BF Nick along as well, I hope he likes a noisy environment !

So, this past Monday Carol had her weekly meeting with Dr Choi who said things are going well. He spoke to the CT scan that was done earlier. The scan was done to check that the cancer on the lung hadn't shifted which would require a re planning step. He said that it showed no change and that the tumor showed signs of shrinkage. As he put it "the cancer doesn't just melt away" it takes time. So it was more for checking for the continuation of the radiation treatment than assessing the overall progress.

Carol is starting to experience some side effects of the radiation and chemo. There may be some thrush starting again in the mouth to which we are restarting the Nystatin. Swallowing is starting to become more painful and the triple mix (lidocaine) is back in the loop. She's also starting to show some skin burning (like a sunburn) mostly on her back, a little cream helps that out.

Today we went in as usual for the labs, infusion and radiation but when we met with Dr.s Stover and Heist they said that Carol's blood counts in a couple areas were too low to receive chemo and radiation. Instead she had a bag of fluids infused to be sure she is hydrated. More labs will be done on Friday to assess whether radiation can continue then more labs next week.

Even so, tomorrow (Thursday) the appointments for the SRS planning will take place. She will receive three small metal beads implanted to the skull to make the delivery of the radiation highly accurate (they triangulate off them). A new mask will be made as well. The SRS is still scheduled for the 22nd.

Looking forward to getting together with family.....

Bumps in the Road

December 19, 2011

Today when Carol goes in she has to first go get bloodwork done to see how the counts are doing. If they are improving then radiation can continue. Last Friday they had dropped even further which gave enough concern to keep her home to shield from exposure to any infection etc.. She was not able to attend the Giombetti Christmas party. The side effects are showing up more now and we are dealing with treating them.

Dr Choi had us back off the steroids last Monday to every other day and I think the same thing is happening again. Carol is very fatigued and showing signs of difficulty thinking and speaking again. I'm guessing at today's weekly meeting with Dr Choi he may up the dose again, we shall see.

The SRS is still scheduled for the 22nd but I'm not sure if that will take place if the counts are not up. She did go for the SRS planning appointment last week. She was fitted for the head restraint but when the Dr came in to do the metal bead implants he said they were not going to do them on account of the low blood counts. He said they would not do them at all and that there are other methods to accomplish the same thing, it just takes a little longer at treatment time.

We shall see what today brings....

Time to Get Some Units

December 20, 2011

Met with Dr Choi and Dr Pretz for the weekly update. Carol's counts are still down but show an uptrend albeit very small. They decided it would be best if she had a blood transfusion so we can resume treatment. They were able to finagle us in this morning so it's off to MGH to get Carol some units !

Go units....Go !!!

Got into MGH around 11:30am. It seemed like this was going to be pretty easy however Carol's veins were not cooperating. As Leah put it her veins are "pooped" from all the

sticks and chemo and radiation...

Took 5 tries !!! today to get an IV in that was OK. Each time they thought they had it, it failed. They called in the Boss, a very experienced RN who was able to get the job done. By now it was 2ish and the infusion took about another 2 1/2 hrs.

While Carol was being infused Dr Willers (who will perform the SRS) came to visit. He said they would like to do the SRS in two lower doses across two days, this Thursday and Friday, instead of one big one. He was concerned that Carol's current condition along with what he saw on the last scan could pose a more serious risk if they deliver one large treatment.

Tomorrow (Wednesday) Carol will start with labs then meet with Dr(s) Heist and Stover as usual and I suspect chemo will be given if the blood infusion has helped. Regular chest radiation after that may be done as well.

"The difference between the impossible and the possible lies in a person's determination."

Tommy Lasorda, baseball
manager

34 Down 3 To Go

December 27, 2011

Well Christmas (the day) has come and gone and Carol is one step closer to finishing the radiation treatment to the chest. She had the SRS done to the brain last week which was broken into two separate doses. It has taken its toll and she is pretty much back in the situation she was after the whole head treatment in that she has trouble articulating and comprehending along with the side effects of the chest radiation in which she is now struggling to eat and drink. Three more treatments to the chest ending this Friday will complete that part. From here it is regular check ins and medication adjustments to get her back to an improvement trend. There may be the last two chemo treatments to come further down the road in January but nothing is scheduled at this point.

I was able to get Carol out to the Lombardo Christmas gathering, however it was short

lived and she wanted to return home after a couple hours. We were at niece Kim's this year in Taunton so the long ride didn't help. It was nice to see the new "little ones" ...generations to come.

A very Merry Christmas and Happy New Year to **all** ! and thanks for all the support you have shared over the last 5 months, it is truly appreciated.

I Care

By Joanna Fuchs

I'm sending this to let you know
I think of you each day,
And pray for your recovery,
Hoping soon you'll be okay.

You're going through a lot right now;
You're treatments can be trying;
Remember while you do them
It's your problem you're defying.

Hold on to your positive attitude,
And when things get hard to bear,
Know that I am here for you;
Remember that I care.

And when you're well and flourishing,
Look back and realize,
You learned what you were made of;
That's a reward that satisfies!

I believe in you; You can do it!

Radiation Complete

December 30, 2011

[Radiation Complete](#)

Rough Stretch

January 6, 2012

Going through a rough stretch, dealing with side effects from treatments. MRI on brain that was scheduled for later this month has been pushed up to today, going to MGH Imaging West / Waltham this morning for 10am scan.

Tomorrow

January 10, 2012

Carol has a regular scheduled Wednesday appointment tomorrow with the medical oncologist Dr Heist at Noon, we hope to hear results from the MRI and see what's in store ahead. She is still struggling with cognitive ability, is fatigued and spends most time sleeping/napping. She had a visit to the Dermatologist today (Nancy took her) where they did a deeper biopsy on the ear sore which will supposedly "cure" it as well.

See what tomorrow brings....

The truth is you don't know what is going to happen tomorrow. Life is a crazy ride, and nothing is guaranteed.

~Eminem~

Go Pats !

January 11, 2012

Today went well, labs were good, blood counts and such on the rise albeit a little sugar level problem, hmmm maybe too much chocolate ? Met with Dr Heist and she was

pleased with Carol's progress. She said it's a slow process and thinks Carol is doing great. She said the MRI showed no change and appears the tumor is stable. They think it's still some inflammation from the SRS that's causing Carol's cognitive and speech trouble. Dr Heist said lets try and start reducing the steroids and keep close watch. Getting down off the steroids should help with side effects.

The next milestone will be in a couple weeks when a PET/CT scan is scheduled. That should give us a better look at the whole picture.

I'm hoping to get Carol out of the house for something other than hospital visits this coming weekend. Might try and take in the Ashland girls varsity basketball game on Friday. Our good friends the Simeone's have also invited us over on Saturday to watch the Patriots, I hope Carol is up to it...Go Pats !!!

Go Carol !

January 21, 2012

Alright, the Pats did their thing now it's time for Carol to do her thing !

Had a visit to Dr Pirl and he adjusted Carol's meds, I think it may be helping, she has been doing better in most aspects except for back pain and weakness in the lower extremities.

We did get out for the girls Bball game last Friday and it was a good night not only did Carol last the whole game we went out with "the gang" afterwards to O'Connell's for dinner. To top that off the Pats got the win and we witnessed that at the Simeone's.

Had a visit with Dr Dietrich (neurology) haven't seen him since the first week Carol was in at MGH. He's great this guy is top of the game

<http://www.massgeneral.org/doctors/doctor.aspx?id=17983>

He said Carol's symptoms are most likely due to the side effects of treatment and they expect a continued improvement over the coming weeks. Dr Dietrich said to start the decrease of steroids and that should help with her symptoms.

Next milestone will be the PET/CT scan which is due up next Thursday.

So we will be at Simeone's again this Sunday to watch the Pats "Do It" once again as

well, Go Pats... Superbowl all the way !

Unfortunately I must get Kristen back up to UNH first, she has had a nice vacation but it's back at it now.

It's not whether you get knocked down, it's whether you get up.

~Vince Lombardi~

A Turn

January 29, 2012

A change in plans for Carol's treatment has occurred therefore we must be in at MGH Monday morning first thing.

The last PET/CT scan showed Carol has a small blood clot in the lung and the cancer appears to be spreading to the bone/spine T10.

They want to do ultra sound on the legs first thing to check for clotting there. It appears she must chose more chemo or opt for palliative care at this point

"Love as much as you can, by all the means you can, in all the ways you can, in all the places you can, at all the times you can, to all the people you can, as long as ever you can." - anonymous

Learn Something New Every Day

January 30, 2012

I guess today went like Mondays are known to go. We woke up !
I'll take that as a gimme and off to that great big building in the city they call MGH we

went. Carol's first tour of duty was with the imaging dept to get an ultrasound on her legs to check for clots. They said they wanted to check just in case so they would know what to expect if any should head north. So Carol settled in as did her sis Mary and I and we watched the tech do her thing, the equipment is amazing as any of you who had kids probably know, this thing was DETAILED. So as the "student" started to scan she starts marking dark blob after dark blob and Mary and I looked at each other with a look that said "no way". Well once that was over and we met with Dr Heist we found out it was "no Way" what we thought were clots the imaging showed, were in fact NOT. Go figure, you gotta go to college to read this stuff !
So A good thing✓

Then comes the not so good thing, there is signs in the liver as well. The options are take another round of chemo and hope a different drug will slow the inevitable advance or opt to do nothing and take palliative care only. My brave wife who's birthday is coming up on the 19th has consented to try the chemo with the "see how that goes" attitude. So we will see how that goes starting Feb 8th.

We headed over to radiation oncology, as I had written in my "bible" book >Dr Choi 1pm<. They looked at me sideways when we checked in, I guess that change never filtered down to me? Anyway, as always it seems, if you show up they will see you. So we chatted with Dr Choi who pointed out that Carol's lungs are clearer, the radiation did it's job there... A good thing ✓

It's the insidiousness of the disease, the little trouble maker metastasis.

Carol has been doing well all things considered, she is much better cognitively, speaking etc. however still fatigued and weak in the legs. Eating well (ok I had to get sugar free chocolate stuff !) even started toying on her laptop...I see some stuff printed out that I don't have the strength to pick up and process right now.

So I did learn something today....A single image tells a thousand stories...

"Love as much as you can, by all the means you can, in all the ways you can, in all the places you can, at all the times you can, to all the people you can, as long as ever you can." - anonymous

Round 2

February 9, 2012

Everything went better than expected yesterday with Carol's first treatment with a new drug Alimta. She was so concerned about side effects from this one but I think "Calling All Angels" has worked, she has no symptoms as of this point. I suspect she will tolerate it just like the first round and continue taking future infusions as well. Her nurse Leah said she didn't know of a case that anyone was really sick. They would continue in three week intervals. The next infusion is in the book for February 29th. The next imaging is scheduled for March 7th, this day I hope the Angels will be with us again.

All in all Carol is doing OK, a little more motivation I see and the increased appetite for sweets continues. That reminds me...next week is ♥ day !

"Perseverance is not a long race; it is many short races one after another."

Walter Elliott

Another Year Older

February 21, 2012

Well here it is February 21st and Carol and I are another year older ! Day by day, not much has transpired. Carol and I got out a couple times in the past weeks for eats and to take in a girls basketball game that's about it. She has been pretty much the same, very tired, back hurts and a little thrush returning which has prompted the restarting of Nystatin and Lidocaine mouth swishing.

She has an appointment tomorrow with Dr Heist just to check in. They were concerned with an elevated count in the liver which medications were adjusted for and they want to keep a close eye on.

She is scheduled to receive another round of Alimta next Wednesday after that there will

be a MRI done on March 7th to see how things are going.

Relay For Life - Caring For Carol

http://main.acsevents.org/site/TR/RelayForLife/RFLFY12NE?px=7153000&pg=personal&fr_id=41350

A Turn

February 29, 2012

Last couple days Carol has become more prone to respiratory distress, only just getting up and a few steps and she was working for air.

We had a scheduled appointment with Dr Heist today and chemo was scheduled, however Carol's current condition wasn't going to allow that to happen and in fact did not. Dr Heist after examining her said she would like to get a CT/PE of the chest to see what's going on and go from there. She was concerned about the existing clots they saw before, and with the change (for the worse) in Carol's cognitive and speaking she suspected the brain tumor is still a problem. She said blood thinners would be the course of action if not for the brain metastases and that's why, get the scan first.

I took Carol and got the scan done then we returned right away back to Dr Heist to discuss the results. Wasn't what we wanted to hear. The scan showed there is fluid build up around the lung in the Pleural cavity due to the cancer. Checking on the clots the Dr said the existing ones were the same if not reduced however there are others now in the other side. Dr Heist at this point decided to admit Carol and schedule a procedure to drain the chest and get an MRI on the head.

We checked in to the Lunder building and settled in. They gave Carol a little Oxygen and a couple nebulizers. She was still in distress with a little relief. Mike, Nancy and Rachael came in and stayed with us all afternoon into the evening. Carol got lucky and the MRI was done before I left for home, so now it's just get the chest drained to relieve the pressure on the lung and hope that stops the shortness of breath tomorrow morning 8AM.



"Nothing in life is to be feared, only understood." - Madame Marie Curie

Back Home

March 3, 2012

Carol was discharged from MGH last night after a two night stay. She is at home and is now taking Oxygen to help her breathing. She had a chest catheter inserted and currently will drain it once a day while monitoring the output.

Spring

March 9, 2012



Carol had an appointment this past Wednesday with Dr Heist. It was to follow up after her stay in the hospital. She has been doing OK thus far, since having the chest catheter and taking a little oxygen, she is at least not experiencing respiratory distress anymore.

Her appetite is waning and only takes a bite or two here and there. At this point there is not much else to do, the second round chemo Alimta was ineffective. Dr Heist said there was another drug that could be tried but positive response to it would be less than a ten percent chance and the side effects could be severe. Carol has decided not to take further chemo treatment. The plan is we will be making contact with Hospice in the next week to have them come in and evaluate. They can be of help earlier rather than later at this point (not like the old days). It's hard for the doctors to put a definitive prognosis out there and as Dr Heist said herself "they suck at it". That being said Dr Heist did offer us her prognosis and said Carol has weeks to months, not days...not years.

Kristen is home from UNH for spring break and we will enjoy her company. Maybe the weather will cooperate and get warmer out so we can try and get Carol out in the fresh air !

God, give us grace to accept with serenity
the things that cannot be
changed,
Courage to change the things
which should be changed,
and the
Wisdom to distinguish
the one from the other.

March 19, 2012



Had family over Sunday for a visit. It was nice having them around. Kristen has returned to UNH after her spring break.

Carol is now in the Hospice care here at home. She is still up, and able to participate to some degree. Hospice nurse is on a once a week schedule for now. She couldn't stand the bed (mattress) as delivered so we are on a third permutation which still hasn't seemed to "do the trick" maybe getting her out to try some options at Jordan's might be needed to get what she wants.

Father Paul Clifford from Hopkinton stopped in and administered anointing of the sick for Carol.

Remember that God restores the soul

April 1, 2012



Home health aid will start tomorrow, four days a week, couple hours in the mornings. Hospice nurse now visiting twice a week and once over the weekends. Carol is having a harder time now when she tries to get up or move about. Started a low dose of morphine to help her with breathing and possibly sleeping through a little longer. She stirs pretty much every hour or so to get comfortable, hopefully this will help.

He is our Shepherd and restores our soul (Psalm 23:1). Even if our physical bodies are falling apart, He refreshes and renews the inner man (2 Corinthians 4:16). Although this earthly body will eventually be destroyed we will get one not made with human hands, eternal in the heavens (2 Corinthians 5:1). We look forward to an inheritance in heaven that is incorruptible, undefiled and that doesn't fade away (1 Peter 1:4). When we are absent in the body, we will be present with the Lord (2 Corinthians 5:8).

The Road Home

April 5, 2012

May God bless as Carol makes the final turn on her journey home. The next week/s will be both a blessing and a great loss.

Thank you all for the Love and support you have shown her these past eight months.

“Life is a great big canvas, and you should throw all the paint on it you can.”-- Danny Kaye

At Peace

April 10, 2012



Carol was called home to heaven last night surrounded by family. She is in a better place now, no more pain, no more appointments to deal with. May she rest in peace and her legacy live on in all of us.

May God bless

Calling hours 2 - 5 pm Sunday April 15th
Matarese Funeral Home Ashland, Ma

<http://www.mataresefuneral.com/sitemaker/sites/matare0/obit.cgi?user=608149Giombetti>

Funeral Mass 9 am Monday April 16th at St Cecelia's, Ashland.
Gathering at the parish family center across the street from the church immediately after Mass.

How do you capture the essence and the spirit of a person's life? Where do you begin?

When Carol received her diagnosis last August, one of the first things she told Fred was that she wanted to write her own eulogy. She wanted to let all of us know how very much she loved us and how thankful she was for us. She wanted to be the one to tell us how much we meant to her. Carol loved being a part of two large families, the Lombardos and the Giombettis. If you are a member of either family, you know it is true. She was so proud of Fred and Eric and Kristen. She was equally proud of the accomplishments of her many nieces and nephews. If all of us here just think back to the times that she was there for us, unasked - if we all think back to so many of the little things and the special effort put into gifts given, well, you know you were loved by Carol. She said that she had so many people to thank for all their kindnesses and for just being her friend. Unfortunately, Carol was never able to get this task done. So we hope she doesn't mind that we took the liberty of jotting down our own thoughts.

How do you capture the essence and the spirit of a person's life? Where do you begin? First of all, when we think of Carol, we smile. Carol had that quirky Lombardo sense of humor. She always had a joke or something to say that would make you laugh. She was an amazing story-teller and was just plain fun to be around. Before they were blessed with Eric and Kristen, Carol and Fred orchestrated countless adventures for their nieces and nephews. They went on vacations to Maine, Greendale, or the Grove at Cape Cod. There were camping trips in the popup trailer, and sleepovers at their apartment. These adventures always featured lots of belly laughs, silly songs, all sorts of junk food, late bedtimes, and falling asleep watching TV. Carol was also a world-class organizer, planner, and list-maker. She managed the summer

vacation schedule for the Giombetti cottage in Dennisport. Every February or March her sisters-in-law would receive the new order for picking their weeks, along with a witty poem written by Carol. Carol coordinated payment of the annual cottage bills, too – again, mailing everything to her sisters in law so that she was sure to get reimbursed! And then there were all those wedding and baby shower invitations. Whenever one arrived in the mail, Carol would be the one to pull up the gift registry and call her sisters or sisters-in-law so everyone could go in on an “Auntie gift.” The day of the shower would arrive and Carol would pick everyone up. Off they went in the “Auntie van” and the fun would begin. During one surprise wedding anniversary party, Carol arrived extra early to help with set-up. But she didn’t just help: she came armed with a detailed “to-do list” that she posted prominently on the fridge door, complete with a pencil on a string that she taped right next to the list. As guests began to arrive and ask what they could do, Carol directed them to read the list, do the next thing on it, and cross it off with the pencil. Kristen’s softball team benefited from Carol’s organizational skills, too. She was a tireless raffle ticket-seller, snack shack operator, and all-around coordinator of details. She was so good at this, in fact, that one of the coaches nicknamed Carol “The Commish”. But Carol was so much more than funny and super-organized. She was committed to her family and friends. As her niece Kathy put it so beautifully, “Carol’s blessing in my life was simply that she was there. It was the ministry of presence.” Carol was there for all of the special people in her life. She did lots of little things “just because” – and those little things showed her great love for us. Maybe she bought you a necklace with beads that spelled out your name, or taught you how to cook a favorite family recipe. Perhaps you were one of the Craft Girls, who met every single Wednesday night for many years to sew and stitch and talk about weddings, babies, jobs, and the tremendous joys and stresses in our

lives. Maybe Carol presented you with a “Carol ornament” for your Christmas tree that she picked out especially for you. Maybe she made sure that she always had lots of your favorite snacks on hand. Or she taught you all the words to the Janis Joplin song “Me and Bobby McGee” so you could sing it with her – loudly – in the truck on the long drive up to Greendale. Perhaps she played cribbage with you – and probably won – while the waves splashed over the jetties and the seagulls flew overhead at the Grove. Or maybe you were one of the many dear friends who were lucky enough to enjoy her company during Kristen’s many softball games and tournaments. Carol was a wife, mother, sister, auntie, and friend – she was also her mother’s daughter in many ways and, like her mother, would insist that we remember the following three things during this sad time:

1. Laugh. When it hurts, cry a bit. But then laugh, even if it is awkward. If you have to laugh until tears are streaming down your face, then so be it.
2. Much like a tried and true ravioli recipe, there is both an order and a reason to the way things are – and there’s no good that can come out of messing with that. And for the record, that ravioli recipe does NOT include cinnamon, squash, spinach, road kill, or M&Ms.
3. Continue living. It’s OK to be upset and hurt, but don’t let life pass you by. Carol’s passing has left a void in our lives, but not in our hearts. Her spirit will live on and she will remain with us always. We love you, Carol. Thank you for loving us. God Speed.