

ALL of it

The story of my Bout with
Acute Lymphoblastic Leukemia

By Cathy Doser

When I was 54, I had a life-threatening disease. Let me tell you how it happened.

On March 9th of 2010, I found that I was more and more tired. It got to the point that I had to literally lay my head down on the desk at work. I knew something was wrong, but I thought I had the worst Flu ever! So, I bundled myself off to my Primary Doctor's office, for an emergency visit. Boy, was I glad that I did that! It saved my life! They happened to have an opening the next day. So, I went in, and was checked out. The substitute doctor for my regular doctor ordered up some tests, mainly in the lab, where they would draw blood, but he wanted me to go visit the **PET** scan machine (**Positron Emission Tomography**, a type of imaging test that uses a radioactive substance called a tracer to look for disease in the body), up in Bellevue, from Burien (about 19 miles), so that they could look at my lungs, to see if I was properly **effusing** oxygen through my lungs, to see if there was something obviously wrong with them, like a tumor. Because they are so expensive, they only have a few **PET** machines at Group Health Cooperative, and didn't have them out at the clinics, where I was at when they were checking me out.

So, I got in my van and drove to Bellevue (*which I should never have been let to do, as you'll find out now*). I was in the PET scanner, and I just finished, and they extracted me from the **PET** tube. They had an urgent message for me. They had to take me to the Emergency Room, right away. I was quite surprised at that, and asked "Why?"

The nurse that was attending me said, "Well, it seems that you're almost out of blood. According to the tests you just did at the Clinic, you have Leukemia!" she said to me, matter-of-factly. She was just signing my Death Warrant. This form of Leukemia, for Adults, is very deadly, like around 70% deadly. It seems that I was down a pint or so of blood, and should never have been allowed on the road, in that condition! My Complete Blood Count (**CBC**) said that my White Blood count was way off, and my Red Blood count was dangerously low, and my Platelet count was 1/5th of normal. That means if I got a cut, I might have bled to death, because of the low Platelet count! That is the classic signs of Leukemia.

Here's what the Complete Blood Count said I had on 3/9/2010. Notice the LL's, that means extra low.

COMPONENT	YOUR VALUE	STANDARD RANGE	FLAG
WBC	3.0 K/uL	4.0 - 10.7 K/uL	L
RBC	2.18 10*6	3.6 - 5.0 10*6	L
HEMOGLOBIN	7.1 GM/DL	11.4 - 15.5 GM/DL	L
HEMATOCRIT	20 %	36 - 46 %	LL
MCV	91	80 - 98	
MCH	33	27 - 34	
MCHC	36 %	33 - 37 %	
RDW	15.1	8.0 - 18.5	
PLATELET COUNT	27 10*3	140 - 450 10*3	LL
Neutrophils, Absolute		2.00 - 7.30 K/uL	
Lymphocytes, Absolute		1.00 - 3.40 K/uL	
MONOCYTES, ABSOLUTE		0.00 - 0.80 K/uL	
Eosinophils, Absolute		0.0 - 0.5 K/uL	
Basophils, Absolute		0.0 - 0.2 K/uL	
NRBC/100WBC		0 - 0 /100 wbc	

They rushed me into the Emergency Room, and hooked me up with a pint of the finest, aged Blood! The Maître'd showed me the bottle... Just kidding! They ended up putting a pint in me. I was held at Overlake Hospital for several days, until I stabilized.

And then they set me up to see an Oncologist, there in Bellevue at the Group Health Oncology Department. I went to see him several days later (Dr. Eric) and he talked to me about having Acute Lymphoblastic Leukemia (ALL). It was a relatively rare kind of Leukemia, for Adults. There isn't a high survival rate for Adults (around 30%). He said that he needed to get a Bone Marrow Biopsy from me, because they had to consider giving me a Bone Marrow Transplant, and it was *the way* they were able to confirm that what I had was ALL. The Bone Marrow Transplant was the newest way to treat people who had Leukemia. It was fraught with problems, though, like Graft Versus Host Disease, but when you were down to *no options*, it was what they had to do. He did the Biopsy, but it was the worst pain I had ever experienced, even more than my Kidney Stones, and that's saying something! That was because he hadn't done a good job of anesthetizing me beforehand in the area of the Biopsy.

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Acute lymphoblastic leukemia, also known as **acute lymphocytic leukemia** or **acute lymphoid leukemia (ALL)**, is an **acute** form of **leukemia**, or **cancer of the white blood cells**, characterized by the overproduction and accumulation of **cancerous**, immature **white blood cells**, known as **lymphoblasts**.^[1] In persons with ALL, lymphoblasts are overproduced in the **bone marrow** and continuously multiply, causing damage and death by inhibiting the production of normal cells (such as **red** and **white blood cells** and **platelets**) in the

bone marrow and by spreading ([infiltrating](#)) to other organs. ALL is most common in childhood, with a peak incidence at 2–5 years of age and another peak in old age.^[1]

The symptoms of ALL are indicative of a reduced production of functional blood cells, because [leukemia](#) wastes the resources of the [bone marrow](#) that are normally used to produce new, functioning blood cells.^[1] These symptoms can include fever, increased risk of infection (especially bacterial infections like [pneumonia](#), due to [neutropenia](#); symptoms of such an infection include [shortness of breath](#), chest pain, cough, vomiting), increased tendency to bleed (due to [thrombocytopenia](#)), and signs indicative of [anemia](#), including [pallor](#), [tachycardia](#) (high heart rate), fatigue, and headache.^[1]

About 6,000 cases are reported in the [United States](#) every year.^[2] Internationally, ALL is more common in Caucasians than in Africans; it is more common in Hispanics and in Latin America.^{[3]:1617[4]} Cure is a realistic goal and is achieved in more than 80% of affected children, although only 20-40% of adults are cured.^[1] "Acute" is defined by the World Health organization standards, in which greater than 20% of the cells in the bone marrow are blasts. Chronic lymphocytic leukemia is defined as having less than 20% blasts in the bone marrow.

ALL was one of the first cancers for which an effective chemotherapeutic treatment was developed. [Antifolates](#) like [aminopterin](#) and [methotrexate](#) were developed in the late 1940s by [Sidney Farber](#) and [Yellapragada Subbarow](#).^{[5][6]} At that time, a doctor did not need a patient's or parent's consent to try an experimental treatment as the [Nuremberg code](#) had not yet been signed. Desperate to save his patients, Farber initially tried [folic acid](#) supplementation as a treatment for ALL. This had disastrous consequences and he likely accelerated the children's deaths.^[6]

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Because the results of the tests had been so dire, and that I was sent to the Emergency Room, I was automatically out from work, until this Leukemia-thing was over. My younger sister, Bonney, called my workplace, and told my boss that I would be out of work, with the ALL, until further notice. Becky took the message, and understood. Little did I know that was going to be so long. The docs had expected me to not make it through this bout with ALL, so they didn't know what to tell my work. But, effectively from March 9, 2010, I was on Extended Medical Leave.

But before the Bone Marrow Transplant could happen, they had to start Chemotherapy on me. I had to be in the Hospital for that, as the side-effects are so severe, that they need to watch over you, closely. Side-effects can be: Fatigue, Pain, Mouth and Throat sores, Diarrhea, Nausea and Vomiting, Constipation, Blood Disorders, Nervous System Effects, Changes in Thinking and Memory, Sexual and Reproductive Issues, Appetite Loss, Hair Loss.

Long-term side effects, include, for example, by some types of chemotherapy may cause permanent damage to the heart, lung, liver, kidneys, or reproductive system. And some people have trouble with thinking, concentrating, and memory for months

or years after treatment, also known as 'Chemobrain'. Nervous System changes can develop after treatment. People who have had chemotherapy may develop side effects that happen months or years after treatment. These are called *late effects*. Cancer survivors also have a higher risk of second cancers later in life.

So, they wheeled me over to Overlake Hospital, from the Group Health Emergency Room, put me under Anesthesia, and I was fitted for a Groshong Port ⁽¹⁾ into my upper right chest area, into my Ventricular valve, through which they would give me my Chemotherapy, and put other IV feeds in, without having to start a lot of IVs. That is called the Induction Round of Chemotherapy. That was the first round of Chemo. It was very hard on me, but I didn't have a choice in the matter. I had to get that to get better. The type of Chemo I got was called Hyper-CVAD, the standard for this kind of Leukemia. This is the Wikipedia explanation of it:

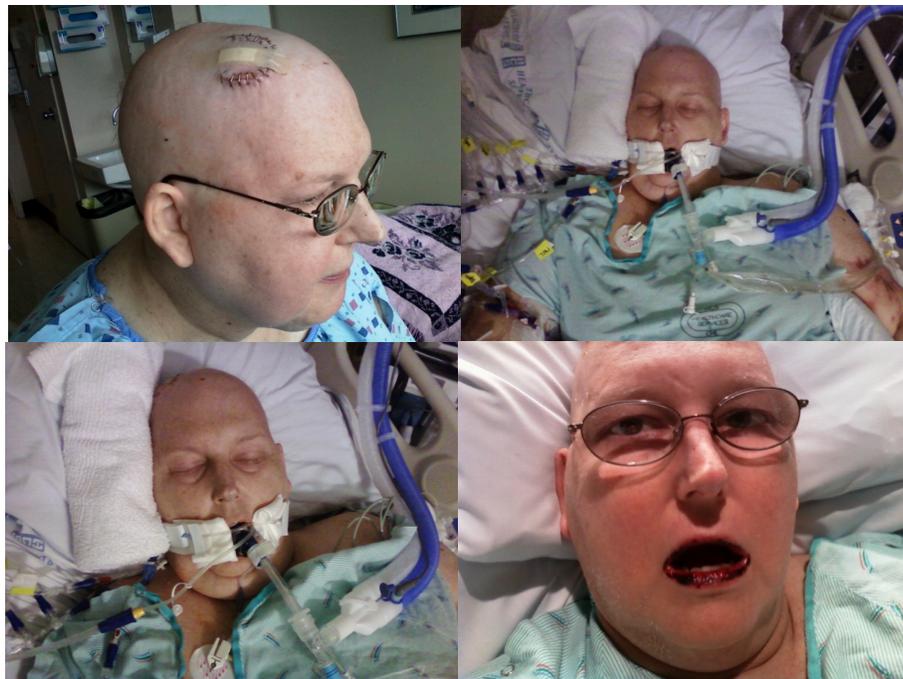
Hyper-CVAD

Hyper-CVAD chemotherapy consists of two combinations of drugs (courses A and B) given in an alternating fashion. The term 'hyper' refers to the hyperfractionated nature of the chemotherapy, which is given in smaller doses, more frequently, to minimize side effects. 'CVAD' is the acronym of the drugs used in course A: [cyclophosphamide](#), [vincristine](#), [doxorubicin](#) (also known by its trade name, Adriamycin), and [dexamethasone](#). Course B consists of [methotrexate](#) and [cytarabine](#). The protocol was originally developed to treat leukemia in young, fit patients, due to its intensity, but has since begun to be used more widely.

One of the side effects for me was that the food started to taste funny. Not ***Metallic***, like many had warned me of, but FUNNY, as in, not the same as it should have tasted! And, it wasn't appetizing! But, that was when I had an appetite. Most of the time, I felt nauseous. After that first round of Chemo, I was let go, to go home. My hair had started to fall out by then, and my younger sister came over to my Apartment and did something *I* requested, that I never thought I would ask somebody to do to me, she cut off my beautiful Red Curly Hair. To give you an idea of why we did that, my hair was beginning to look like a cross between David Letterman's and Donald Trump's. Like a Cat had just made a bed in my Hair. Like a bail of straw. Yech! My formerly Beautiful Red Curly Hair had to go! It was falling out, on it's own, but I just wanted to be done with it in one fell swoop!

After the first round of Chemo, I was sitting home, off work, on a Long Term Disability Medical Leave. I was getting weaker, sicker, and couldn't even go to the store for food. I had to have the Safeway Food Service bring me my food. My sister was trying to get me to take in more Protein, so that I wouldn't be so weak. The Protein Powder they gave me was pretty horrible tasting. Different. Not good. So, I tried to work my way through some Strawberry flavored Carnation Instant Breakfast, with some Protein Powder mixed in. That wasn't great, but I choked it down.

I had to go in for a second round of Chemo, in May of 2010. This time it would also go into my head. To do that, they had to put me under, and inserted what is called an Ommaya Port/Reservoir ⁽²⁾. They had to put me under for that, too, like the Groshong Port in my chest. But this time, it was a much trickier operation, since it was going into my head. I ended up with this horseshoe shaped set of stitches on my bald head, with staples all around it. It looked much worse than it felt. I show pictures of it, just to freak people out. It looks kind of like Telly Savalas, with a Pre-Frontal Lobotomy! They had to drill a hole in my Skull to insert it. Great! The one thing they didn't do? They didn't tell me it was going to be in my head, **for life!** Well, from their point of view, it wasn't possibly going to be for very long. They were sure I wouldn't last long. Me? I planned on being around for a long time! I asked them if it could be taken out. But, the reason they couldn't take it out? After a while, my Brain had grown around the probe into my Brain, and there would have been bleeding, in my Brain, if they had taken it out, which would have been disastrous. So, for the rest of my life, I had to be careful about not bumping into the Port. It would hurt! Note the upper left picture for what the Ommaya Port looked like, after they placed it in me.



It was during the second round of Chemo that the trouble happened. The Chemo did not work well for me. I went into some sort of mental breakdown, a kind of crazed state. The reason why, in a moment.

The whole affair started with me calling my younger Sister, at 4am. I started to talk to her about how I had seen God, and how I now understood her, and her devotion to God. She thought that was great, but knew something was wrong with me, since

I wasn't an overly religious person, and me saying all of this would be out of character.

Shortly after I had got her on the phone, the nurses came rushing in. They knew something was up with me. And since I was getting such dangerous drugs, they were monitoring my movement, and they knew I was up and talking on the phone, which wasn't normal, especially at 4am.

I don't remember all of this, but they got me back into bed, and got the doctors for me, quickly. What had happened was that I was having delusional episodes from a reaction to the Vancomycin antibiotic they were giving me for the MRSA I got from being in the Hospital, in my Groshong Port. I started to have more serious reactions to the Chemo, I was going into a Coma, and they ended up having to intubate me (breathing tube down your throat), and then tie my hands off to the side of my bed so that I wouldn't pull the tube out of my throat. There's no worse feeling for someone who has Claustrophobia! But, I didn't know it, while I was in that Coma.

The other thing that started to happen to me in the ICU was that I started to get Stevens-Johnson Syndrome, which is where your body reacts badly to a medicine, the antibiotic in this case. That was another reaction to the Vancomycin. It seems I'm really allergic to it. You can see it in the pictures above, especially on my arms. Here's the whole medical description:

“Stevens–Johnson Syndrome, a form of toxic epidermal necrolysis, is a life-threatening skin condition, in which cell death causes the epidermis to separate from the dermis. The syndrome is thought to be a hypersensitivity complex that affects the skin and the mucous membranes.”

My skin was going to 'Hell in a Hand Basket!' It was getting *boils* and looked like I had been burned. And, the dead skin kept flaking off. It was gross! I felt like Pig Pen from Peanuts, and when I could finally get out of bed, everywhere I would go, a cloud of dead skin would waft into the air! And, I had these big red splotches all over, especially on my arms.

But I wasn't going anywhere right then. I was in the ICU, and in a Coma. This was in June of 2010. The Methotrexate was also very affecting to me. My younger Sister and her Pastor came and prayed over me. Also, my older Sister had been summoned up to the Hospital, from her home in Camas, Washington, because the doctors said they had something very serious to talk with both sisters about. I had almost died about 6 times by then. My younger Sister had Power of Attorney/Health for me, and had to be in on any decision that was made about/for me, since I was in the Coma.

They talked with the Hospital staff, and the Oncologist, and were told that I wasn't going to recover from my Coma, and that they should plan for the Hospital to take the tube out of my throat, and to put a DNR bracelet on me. DNR means, "Do Not Resuscitate"! The doctor was telling my Sisters that there was no chance for me to wake up from my coma, that they should just let me go. (Obviously, since I'm writing this now, they were full of it. I've continued to live, for seven years since my original diagnosis.)

(After about 10 days, maximum of 13), the Doctors have to take an Intubation Tube out of a person in a Coma and give them a Tracheotomy. They didn't know what to do.) I found out about the intubation tube when I woke up from the Coma with the tube down my throat and my hands tied to the side of the bed, so that I wouldn't try to take the tube out of my throat.

I woke up from the Coma when my older Sister, Marikay, came walking into my ICU room, and said to me, loudly, "What the hell are you doing lying there? Get up, and out of bed!"

And, I woke up! From the sound of my older Sister's voice, I woke up! It was miraculous! She had done what the Doctors couldn't. By talking TO me, and with her voice, she had made contact with me, through the Coma! (Who knows! Maybe because she's my Older Sister, too!)

But, the problems weren't over. The doctors were intent on giving up on me. Since I had responded so badly to the last round of Chemo, they were giving up. The Oncologist said they didn't do any Bone Marrow Transplant, because he said that at the time, I couldn't have withstood the "toxicity" of the Bone Marrow Transplant (BMT). That it would be worse than the Chemo I had been getting. I don't understand, since that was an Extreme Life Saving Measure, anyway. And, since I was going to die, according to them, why not try something that might save my life? I still can't get a straight answer from them on that.

So, in July of 2010, they sent me to the Bailey/Boushay House, a Hospice facility originally set up for HIV/AIDS patients, who were terminal. Since it was part of the Virginia Mason system, I was sent there for Palliative care. I was there about a month. The nurses there are incredible! I was treated so well, there is nothing to complain about! They treated me with Love. And, I don't know how they do it. Because, it's a Hospice facility. They almost always lose their patients! And yet, they still give all of themselves, so much so that you feel covered in Love. They took care of every need I had, and did everything for me, especially because I couldn't do anything for myself. I couldn't clean myself after going to the bathroom. They took care of that. They literally craned me up so that they could get access to all of me. They are selfless.

The one thing that my health care company (Group Health) did for me, seemingly against their position, they signed me up for Physical Therapy, to help me get better from the Debilitation I suffered from not moving around from staying in a Hospital bed for almost 3 months. I could barely move around. Finally, when they got me to the side of the bed, I tried to move my legs, and they didn't do as I commanded. I had to learn how to walk, all over again, at the age of 54. I know it sounds made-up, but I worked on it, during the month I was there, and I got to where I was able to walk, with a walker, down to the Nurses Station, which was almost the length of the building away from my bed, about 80 feet. While I was at the Bailey/Boushay House, I had to keep calling the Physical Therapists, because they didn't show up for our appointments. I was infuriated. I wanted to start doing things on my own again. And they were acting like there was no use in trying to do it, that I was going to die, anyways, so why did I need to get Physical Therapy (PT)? The thing was, I was raring to go! I wanted the PT folks to come and help me, to see how much better I had gotten. That I could now walk, all the way to the Nurse's Station! I think that the walking is one of the things that surprised the Nurses. I had actually gotten better. They weren't used to that from their patients! People getting better? They came to Bailey/Boushay House to die, not get better.

The people at Bailey/Boushay House were wonderful! They were so kind, and giving, and full of love. It must be a hard job, to almost always seeing your patients die. But a crazy thing happened. A year later, I went back to the Bailey/Boushay House, and met with the Nurses I had when I was there. I walked into their area on the Second Floor. They recognized me! And they started to call out my name, and ran out to me, with tears in their eyes! They couldn't believe that I was there, in front of them, standing, and walking on my own! They thought, from what my docs were telling them, that I was going to die, within several months, if not weeks, if not sooner! I was a walking miracle for them! They just couldn't believe I was still alive. It was a joyous time! I loved being able to walk back up to the Nurses Station, where I had struggled to walk up to from my Room 203, all the way down the hall to them at the Nurse's Station. Now I was doing it with ease, without the Walker!

But, before I returned to the Bailey/Boushay House for my first miraculous visit, I had several stops to go to. I was sent from the Bailey/Boushay House to an Adult Family Home in August of 2010, that -I- had to pay for, not Group Health. That was \$8,000/mo. They were sure I was going to die there. They sent a Nurse and a Social Worker out to see me, like they had at the Bailey-Boushay House, and were sure I wasn't going to do so well. I did so well, that I ended up making dinner for the gang, one of my favorites, Pork Chow Mein! And I stood there in the kitchen, cutting up all the vegetables, and frying them up. And I made Fried Rice to go along with the Chow Mein! So, it was obvious to my housemates that I wasn't about to croak. I didn't do much when I was at the Adult Family Home, in Magnolia, but I did something they didn't expect me to do, Live. They were sure I was going to Die, according to the Doctors. But I refused to Die. When I drove away from the home in

my Van, I'm sure they were thinking that it was the last time I'd be seen, and that I was driving off into the sunset! To me, I was just driving to Ocean Shores!

But, I was paying for that house stay, and it was \$8,000 a month, and I just couldn't afford to stay there any longer. The only choice I had, because my Sisters had moved me out of my apartment, when they were told I wouldn't be around another month, by the doctors, was to go to the family vacation home in Ocean Shores, all by myself, and live out there until I got better. At least that's why *I* moved out there. I'm sure my doctors weren't so sure about what I was doing. It was September of 2010, and the Health Insurance people sent a Hospice Nurse out weekly to check up on me, take my Blood Pressure and other vitals, and checked out how I was doing. The only bad time I had there was when I fell, out in the Garage Driveway, and couldn't get up easily, by myself. I had to crawl over to the Van, parked in the Garage/Overhang, and pull myself up. If I hadn't been able to do that, the neighbor who was keeping an eye out for me would have looked over at our Ocean Shores house, and hopefully called the Fire Department to come out and save me.

I even had a house-cleaning woman come out weekly and take care of the place, because I didn't have the strength to do so myself. But I guess I had enough strength to make my own meals. They never offered a person to help me out with that chore. It's lucky I wasn't as debilitated as they said I was. I could still do the simple menu chores. I also had the strength to go to the grocery store. Another thing that I'm sure my Health Insurance docs didn't think I could do.

Otherwise, I was doing *fine*! I would drive into Olympia to go see the Group Health doctor, so that he could check up on me, and do my Complete Blood Counts (CBC), to see if the Leukemia was coming back. It wasn't, so, after staying out there for a month, and feeling so much better, and my numbers getting better in my CBC, I decided to go back to work. I had to have the doctor approve me for coming back to work. He did, because he saw that I was strong enough to work, and I didn't seem to have any left-over conditions from the Leukemia!

So, I called back to my new boss only to find out that he had moved on, and there was a new person in charge of my group. I now think that she didn't appreciate being told that she had to take somebody into her group. I never did get along with her, and I think that is the reason that I got bad reviews from her, and ultimately was laid off, five years later, even though I had beat Leukemia, and had 31 years at Boeing, 25 in IT.

I had to go through Boeing Medical, for them to also approve me coming back to work, from my near-death episode with Leukemia. They cleared me, especially after seeing the letter from my Group Health doctor.

After that, I came back to work again on MyBoeingFleet. I ended up working there for another five years, until I was laid-off because of the less than glowing **subjective** reviews I had from that Manager. She and I just never got along, and I had been trying to find another place to transfer to, but I didn't do that before she was successful in laying me off. But, I was quite successful in going back to work, to being able to work as a normal person again. I've had a major health condition that would ground most people. I had gone through Acute Lymphoblastic Leukemia. It had caused me to be out on Long Term Medical Leave. It was major Health Concern. And yet I thrived! I'm still living after the ALL, from which over 70% of Adults don't recover and make it through. I think I'm a good bet at work. Too bad my last manager didn't think so.

As a final chapter to this story, I went back to the Bailey/Boushay House, after 5 ½ years had passed by. It was now 2015. I met with two of the nurses who had treated me back in 2010. They had been there, 5 years ago, helping me. And, when Craig came off the elevator, first, he recognized me! And his eyes got really big, and he just wanted to hug me! He remembered me, with obvious love in his heart!

"You remember me?" I asked Craig.

"Of course I do!" he exclaimed! "How could I forget you?"

"Well, I didn't think I was -that- memorable! I said.

"Of course you were. Here, let me call somebody else down." And he went to the security station phone, and called upstairs. A moment later, the elevator opened up, and Wendy came out of it.

"Oh, my!" Wendy exclaimed!

She came over to me, and just hugged me so hard!

"I can't believe you're here!" she said to me. She was obviously in disbelief!

"You remember me, too?" I asked her.

"Oh, you bet I do!" Wendy exclaimed.

"Do you remember me asking for my pants, just before I left here?" I asked.

"Oh, you were just so alive!" Craig said. "We were sad to see you leave. But we're so happy to see you here, alive, today!"

“Well, I’m so glad to be here, alive, today! It’s been quite an adventure, the last 5 years! I did come back, after one year from staying here. And the nurses were so glad to see me then! I went to the Second Floor Nurses station, and they came running out to see me. They all hugged me!” I said to Craig and Wendy.

Somehow, I had made an impression on them in 2010, and they still remembered me. Don’t ask me how, you’ll have to ask them! The one thing I do know that might have made me memorable is that back in 2010 I was asking for my Pants on the last week or so there. I was tired of wearing a Hospital gown for nearly three months. My Sister thought that was really funny! I was demanding my pants! And, I did get them when I left the facility, and went to the Adult Family Home.

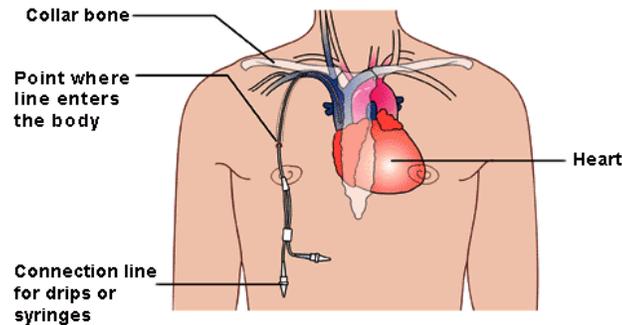
Those nurses don’t get to see their patients continue on, and be real live humans after going to Bailey/Boushay, and I was just a contradiction to that. And I was glad to be that. To bring joy back to those nurses was absolutely my pleasure! They totally deserve it!

So, here I live, over 5 years past my “Best By” date, making a liar out of those Docs, who said I would be finished back then. Not only am I happy that they were wrong, I’m happy to be doing all of the things I do now, to help others, since I’ve had this extra time. That is the part that’s made me most happy!

Cathy Doser
February 27, 2017
Renton, Washington

Terms

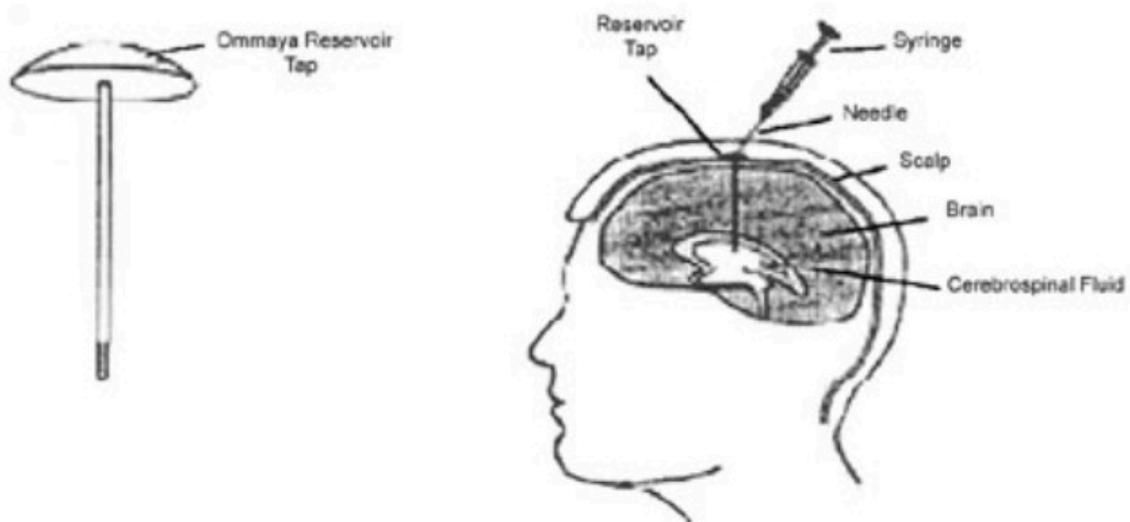
(1) Groshong Port



A Groshong catheter is a long hollow tube made of soft silicone. It has a closed, rounded tip and a three-position valve placed in the side of the catheter near the tip. The valve allows fluids to flow in or out but remains closed when it is not being used. The catheter is commonly referred to as a central venous catheter because it is inserted into the large vein leading directly into the heart.

The catheter has a connector on one end that is used to enter the tube. An injection cap, infusion line, or syringe can be attached to the end of the connector.

(2) Ommaya Port/Reservoir



What is an Ommaya Port/Reservoir?

The Ommaya Port/Reservoir is a device through which fluids can be put into, or removed, from around the brain. There are two parts to the Ommaya; a small plastic dome-like container or port that is put under the scalp and a small tube (or catheter) coming off from the dome. The end of the tube is directed into a open space in the brain called a ventricle. The cells in the ventricles produce Cerebral Spinal Fluid (CSF). The CSF flows around the brain and the spinal cord to provide a protective cushion and nutrients.

What is the purpose of the Ommaya Port/Reservoir?

The Ommaya Port/Reservoir is used to take out a sample of the fluid or give chemotherapy directly into the fluid surrounding the brain and spinal cord. This method of giving chemotherapy is called intrathecal chemotherapy. Intrathecal chemotherapy is administered so the drug(s) can get directly into the area around the brain and spinal cord where cancer cells may be. There is a network of blood vessels surrounding the brain that act as a screen (blood-brain barrier). This blood-brain barrier does not allow most chemotherapy to get from the bloodstream to the brain and spinal cord. Intrathecal chemotherapy is used to by-pass this barrier, allowing chemotherapy to reach cancer cells.

How is the Ommaya Port/Reservoir put in?

A surgeon will perform this surgical procedure in the Hospital under general anesthesia. Your head will be shaved in the area that the reservoir is to be placed. The Ommaya Port/Reservoir is placed under the skin on the head and then the tube or catheter is positioned through the skull into a ventricle in the brain.

Things to watch for immediately after the Ommaya is placed:

Keep the area dry until the stitches (or staples) are removed. Watch for signs of infection such as redness, tenderness or drainage at the incision site, fever greater than 100.5, headache with or without vomiting, or neck stiffness.

After the Ommaya Port/Reservoir is put in you will have a small bump on your head. This is normal. Once the surgical incision from the Ommaya Port/Reservoir is healed, no special care is needed for the site. You can participate in normal activities. You may wash your hair.