



**Leukemia / Bone Marrow Transplant (BMT)
Program of British Columbia**

Patient Education Manual

Survivors'

Stories

About these stories

This booklet features stories written by patients of the Leukemia/Bone Marrow Transplant Program of British Columbia.

By sharing their journey and experience, these patients and their caregivers wish to give you a sense of hope and encouragement during this most difficult time.

Acknowledgements

The Leukemia/BMT Program of British Columbia is most grateful to the patients and their caregivers who contributed their time and stories to make this booklet a reality. Their positive attitude, honesty, humour and passion about helping other patients has inspired, enriched and humbled us all.



**Leukemia / Bone Marrow Transplant (BMT)
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Well,
I can dream,
can't I? When it
happens, that's
a bonus.

The
primary
change in life after
BMT seems to be
velocity. He still does
all the things he loves
but now has a far
greater appreciation
of doing them.

The realization
that I needed assistance
allowed me to regain my
equilibrium. Learning to allow
people to help was a great
gift to me.

Surviving
means the
possibility to see
my daughter graduate
and maybe even get
married. I am not
going to limit the
possibilities.

Her
success
lies in her
great sense
of humour,
determination,
'just do it'
attitude and the
unselfish support
from friends,
neighbours,
doctors,
nurses and
family.

Before
cancer, I was
consumed with
fear and in a sense
embraced Death.
Now I have fully
embraced Life.

My story
is not really one of
survival but one of hope. May you
be filled with my same hope and may
you hold that hope close to your heart
while you undergo treatment.

I now
focus on the moment.

Yes, there is a chance I'll relapse
again, but that's not the case right now.

Right now I can still enjoy life.

Best of all, I woke up this morning to
enjoy it all again.

I actually
accepted my
illness as a blessing
because my family
became much closer
to each other and
to God.

I can be changed by
what happens to me.
I refuse to be
reduced by it.

Remember,
there is life
after cancer
and only you
can decide
what that life
will be.

I decided
I would treat
this as another
adventure. I would
plan for the worst
but expect the best.
This philosophy has
served me well.

I am
not a patient.
I am not a statistic.
I am a survivor. Living
proof that miracles
do happen.

I try not
to fear and feel that
there are many people working
to find a cure. I take life on a daily
basis and enjoy every day as it comes.
And I look for rainbows
in the sky.

Our illusion
about control of the future has
vanished. We are navigating the path of
survivors, and we are ready to go
where it takes us.

Never
stop
believing.

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Leukemia

Stories



**Leukemia / Bone Marrow Transplant (BMT)
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John's Story

John Routely was diagnosed with acute lymphoblastic leukemia (ALL) in 1999

OUR daughter was born just nine months prior to my diagnosis. She is our first and only daughter. I was going to Capilano College in North Vancouver taking the Registered Care Aid Program. I only had my practicum left. I was very active hiking and exploring around North Vancouver. I just became a Christian and was very involved with my new church family. I was thoroughly blessed: enjoying being a new father and feeling on top of the world. My wife and I were excited about starting a family and were planning our future with no idea that I would shortly be diagnosed with such a serious, life-threatening illness.

When I was 31, I was diagnosed in December 1999 with acute lymphoblastic leukemia (ALL), Philadelphia chromosome positive. I felt disbelief at first, then scared; everything was happening so fast. I went to Emergency with jaundice one evening and was told my blood work was “wonky”. The WBC was significantly elevated, and the next day I had to have a bone marrow biopsy that confirmed acute lymphoblastic leukemia. Then the following day chemotherapy was started. My parents rushed down from Smithers. I cannot even begin to describe the shock our family was in after learning I had such an aggressive leukemia. Family and friends were contacted and began supporting and praying for us.

I felt disbelief at first, then scared; everything was happening so fast.

I went through one round of chemotherapy. Then I looked for alternative therapies. I relapsed in July 2000 and had an unrelated bone marrow transplant on August 17th, 2000. It was a 6/6 match from a German donor.

Over the next couple of years, I had several hospital admissions totaling over one year as a patient for pneumonia and graft-versus-host disease of the liver and gut. I had one abdominal surgery. Many times I had a poor survival prognosis but was blessed with making it through these difficult times.

I stayed in remission for nearly 2 years after the bone marrow transplant, and relapsed again in 2002. I then went on Gleevec 600 mg orally. I had a very hard time taking it at first (had to take it with a strong anti-nausea medication), but eventually it became easier. Now I take Gleevec 400 mg everyday and have remained in remission ever since. I have had periodic admissions to the hospital for pericarditis, septic shock, and pneumonias. I have chronic hemochromatosis (as a result of genetics and transfusions). I will be doing

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small monthly phlebotomies. I also have kidney and liver damage which is constantly monitored and has been stable for the last few years. I have gone through periods of depression after being chronically unwell for such a long period of time, but my family and medical team is always there to help me. I visit my hematologist every six months now and recently he has been able to do a hematology clinic right here in Prince George to service the northern patients. I have had the same hematologist, Dr. Nevill, for most of my illness and I certainly want to uplift and honour him for all his professional knowledge that has saved my life!! Thank you, Dr. Nevill. I am also thoroughly thankful to my family physician in Prince George who is always there for me and provides such excellent medical care. Thank you Dr. Kelly and Anita, his assistant. All my doctors and medical staff have been excellent both in Vancouver and Prince George, and there has been a lot of them!

Has cancer changed my life? Yes, it has significantly. First, so many of my life goals were changed. My new goal became surviving for my wife, daughter and family. It also became an important goal to rebuild my physical body and to accept the changes in my life. I had to accept my diagnosis and fight the battle with all my physical strength and depend entirely on God.

There are so many people that I am thankful to for all the ways they have supported me and my family. I thank my family, my Mom and Dad, my wife’s family, relatives, friends and my church who have all been there in such a huge way to help. They offered to babysit our daughter, visited me after traveling hundreds of miles, sent cards, gave gifts, brought food, said prayers, recommended every product under the sun to cure me (with good intentions, I admit) and plainly just encouraged us all the time! My wife met many supportive families going through similar situations in the hospital hallways and kitchen. She valued all the support they gave her,

especially the support of one special woman named Yvonne Shuman. And what would I have done without all the hospital staff including the physicians, nurses, dieticians, OTs, porters and housekeepers that were so kind, encouraging, and knowledgeable in medicine and patient care. They all went well over and beyond helping, not only me, but also my wife and daughter. I had two admissions over Christmas and they made it so special for us, despite me being so unwell. Everyone was always respectful of our family’s choices, even when they may have been different than their own values and preferences. Our daughter basically grew up in the hospital and outpatient clinic from age 10 months to 3 years old. Everyone was always patient with us having a young child and allowed the occasional popsicle, in order to prevent the odd tantrum. One particular birthday, when I was nearly considered palliative care, a certain dietician named Yvonne Grohmuller blessed me with a memorable birthday when I weighed only 96 pounds. (My weight today is over 180 pounds.)

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I do not think about reoccurrence because I live day by day, spending my time in meaningful pursuits, enjoying every moment with my wife and daughter.

My lifestyle changed drastically for many years. I was so sick and had no strength for approximately two to three years. I slowly gained some of my strength back and am now able to go for walks, bike rides and play with my daughter. There are a few restrictions that I have. For example, I avoid hazardous activities for falls such as rollerblading because of my low bone density, but I am slowly regaining strength every year. I have cross-country skied, camped and enjoyed short trips with my family recently.

I have not been able to return to work, but some day in the future hope to go into another career choice. Spiritually, this has been a time to learn to trust in our Creator, God, and accept that He is there when we go through sufferings and trials in life. We are now living in Prince George. At the time of my illness we were residents of Vancouver, but moved up north to be around immediate family about six years ago. We are able to enjoy nature and the beauty of this forest region, an area rich in the red pine beetle forests.

My relationship with my daughter and wife has become so close. I am so thankful how my wife has supported me and we have become closer through this experience. We really depend on each other and enjoy our time together as a family. We do not take each other for granted. I have had the chance to really appreciate my life and spend more time with my family. It has been good for all of us to learn more about ourselves and our need for Jesus. I am very aware of

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diet, nutrition and health now more than prior to my diagnosis. We try to avoid a lot of preservatives in food. I avoid smoked meats. I have become mostly a vegetarian and we have a small garden. My wife cooks in a very natural way for us. I do not drink alcohol or smoke. I drink 1 to 2 litres of water a day. I find meaningful time every day with God for strength and coping with stress. I have also let go of anger and practice forgiveness.

The hardest thing about having cancer was thinking why did this happen to me? One seems to blame himself at first, and ask God what did I do wrong? This is where the reality becomes clear that we are living in an imperfect world where children die at young ages and get sick, children starve from lack of food and disease and suffering seems to see no boundaries. To be completely honest, there has been some depression occasionally and searching for my new identity and purpose has got me down in the past and even currently if I am not keeping my life in balance physically, emotionally and spiritually. What has been

hard, at times, is when it appears people are defined by what “they do for a living” and if you do not work, one needs to define their identity themselves and accept it. At these moments of despair, my greatest strength to see me through is my faith and those closest in my life. I

have learned that God is with us in our suffering and trials and gives us the strength to live one day at a time looking to Him as our source of strength! I do not think about reoccurrence because I live day by day, spending my time in meaningful pursuits, enjoying every moment with my wife and daughter. I enjoy reading and being on the internet as well.

Something positive can come out of something negative. I now am blessed with a blood brother, my bone marrow transplant donor who lives in Germany. I have had the opportunity for the last seven years to be in contact with him. Since I have no siblings, the only chance I had medically for survival was an unrelated bone marrow transplant. I was blessed with a perfect bone marrow match to this gentleman. Over the years, we have gotten to know each other quite well. There is a language barrier, but that does not stop this awesome relationship. We send letters, pictures, emails, gifts at Christmas, postcards and even spoke twice with a translator across the ocean. We have both extended invitations to open our homes for a visit one day and it will be a dream come true if we ever could!

Surviving means the possibility to see my daughter, Cassidy, graduate and maybe even get married. I am not going to limit the possibilities. This experience, although initially one might think as very frightening, is not as bad as people think. I can see the blessings in the smaller things of life, the things around me such as nature, family and daily living. It has taught me patience, more understanding towards others who are experiencing troubles whether health or emotional difficulties and I can say that God is there for everyone. He is a prayer away and cares about all His children!

I hope by writing this survival story, I can somehow encourage you with my journey.

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story, I can
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Lisa's Story: "Not Necessarily."

Lisa Lockerby was diagnosed with acute lymphoblastic leukemia (ALL) in 1991

Written by: B. J. Kemp (October 16th, 2003)

"DOES this mean I'm going to die?" Lisa asked innocently to Dr. Nantel, the hematologist at the Vancouver General Hospital. He had just diagnosed her with leukemia.

"Not necessarily" was his reply. These simple words of hope became Lisa's lifeline for the next five months while her treatments pushed her to the edge of death, threatening, but never taking.

Lisa's bone marrow transplant was on January 27th 1992. She was thirty-three years old. It was also her sister's birthday. Lisa was admitted to the hospital on January 19th. For four days they loaded her up with 'humongous doses of chemo.' Then she had three days of total body radiation; everything but the lungs. They were killing off all her bone marrow

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"I barfed for the next three weeks. Then I got sores throughout my mouth, down my throat and into my chest. For three weeks I couldn't even suck ice cubes."

She walked out of the hospital 25 days later, free of leukemia, and with a deeper understanding for the kindness of the human spirit.

to allow her body to accept the marrow from her sister, Gail. One drug was so potent it turned the intravenous line going into her body to cement.

"They take you down so close to death," she said.

Her 39-year-old sister flew in from Ottawa the day before; she was a perfect bone marrow match. At 8 am, they extracted 1 ½ litres of Gail's bone marrow from four places in her hip. They cleaned and washed her marrow, extracting a potentially lethal germ. At 3 pm, the pink gelatinous material was infused into Lisa's main vein. It should have taken 2-4 hours, but for Lisa, it took 9 minutes.

Her
success
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“My heart started pumping so fast. My face went beet red, and I told everyone to leave the room, I was going to be sick. The next day I barfed, and I barfed for the next three weeks, I was barfing from my toes! Then I got mouth sores – cankers throughout my mouth, down my throat and into my chest. For three weeks I couldn’t even suck ice cubes.” She walked out of the hospital 25 days later, free of leukemia, and with a deeper understanding for the kindness of the human spirit.

Lisa is my hero. She embraces life as a gift. She is fortunate to be alive and knows it. Her zest for life oozes out of her sly smile and joyful little laugh that defines her. She looks great; short blond hair, stylishly cut. Make-up accentuating her looks, applied with precision. Her clothes, always co-coordinated. Her success lies in her great sense of humour, determination, ‘just do it’ attitude and the unselfish support from numerous friends, neighbours, doctors, nurses and family.

Lisa and I grew up in the same neighbourhood. We attended school together from Kindergarten to Grade Twelve. Although I don’t see Lisa on a regular basis, our past binds us in a comfortable way. I recently met with Lisa in a small café to try and capture the secret to her recovery.

“Everyone stopped their lives.” She said, “It’s amazing what family do for each other.”

It began Friday October 19th, 1991. Lisa’s family doctor phoned and requested she come to his office. After 3 weeks of suffering from migraines and night sweats, she was looking for answers. He immediately sent her to the hospital for testing. She may have leukemia. Monday morning she was back at the hospital for a bone marrow biopsy. Her anxiety level was contained because she’d been told the results would take one week. However, after a 2:30 pm ultrasound Lisa and her husband Dave were told to go straight to the doctor’s office.

“Do you think they know now?” Lisa asked Dave.

“We went to his office and I knew, I just knew.”

Dr. Nantel broke the news to them.

“He was sad to tell us,” Lisa said. “He’s a year older than I am and his wife is my age and they had children our kids’ age, it was hitting way too close to home for him.”

Always the competitor, Lisa’s response to the diagnosis was, “Okay then, what do we have to do to get through this?” Her acceptance of the disease and unlimited support, helped make Dr. Nantel’s words ‘not necessarily’ come true.

Lisa is the middle child of a family of four. Gail her oldest sister, her bone marrow donor, lived in Ottawa with her two children. Douglas, married, lived in Vancouver, and her younger 25-year-old sister Amanda, was about to embark on a teaching job in Japan.

On the day of her diagnosis, Lisa's parents were at her house preparing dinner for them. Amanda was looking after their children. No one was expecting bad news.

"We walked in, and mom said in a cheery voice 'hi!'. I just stood there." Lisa said, "Our whole world changed right away. My dad sobbed. He didn't want me to see him cry. He went into the bathroom, my mom ran after him, then I ran after her and the three of us were standing in this little bathroom. My mom said, 'Why couldn't this be me?' and I said, 'You know what Mom, I'm younger and I'm stronger and I'll fight this way better than you could. That's the attitude I took on right away the minute I was diagnosed.'"

When I asked Lisa how Amanda contributed to her healthy success her reply was,

"Amanda? What didn't she do? Amanda was fantastic. She came up to me and said, 'Don't worry about a thing. I've got things covered!'" She cancelled her Japan trip, moved into the basement suite, and took over all child care of their 3 and 5-year-old boys. "I didn't have to worry about a thing."

Lisa was in the hospital the next day for five weeks. Her parents stopped their lives. They came every day. Her mom brought her a clean pressed night gown daily and colourful socks to brighten her life. Her dad went to the video store and brought her a different comedy every day. He was available for her 24/7. She could call on him, requesting food to satisfy her bizarre food cravings. Her friends brought her food. Food was delivered to her family. Her best friend Sandy, phoned her every day from Los Angeles. Her husband Dave, visited her every day on his way home from work.

Douglas, her tall blond brother, had wanted so badly to be the donor; he wanted to help. After her transplant she

She got through the worst days through visualization and relaxation. She whisked herself off to Buck Island in the Caribbean, she put her husband Dave into the picture. They lazed in the sun, floated in the crystal blue water, drank, ate and had fun. Then as a surprise for her fortieth birthday, Dave took her off to Buck Island and together they relived her fantasy.



was heavily sedated, and she remembers seeing Douglas, just sitting there beside her for hours on end, being there, in his quiet, gentle way.

Today
she works
for the Cancer
Society. She is a
living example of
her company's
motto: Cancer
can be
beaten!

Lisa's diagnosis sent her body into chaos. She was bombarded for eight weeks with chemo; four weeks in the hospital and four weeks as an outpatient. She received four spinal taps; they took out bone marrow and replaced it with chemo. Ideally you should lay flat for twenty-four hours after a spinal tap, but as an outpatient that's impossible. She was so ill, the chemo made her vomit every day, and every day she had to receive more. Finally the doctor stopped, because he said, it was killing her.

She got through the worst days through visualization and relaxation. Her friend Kelly gave her listening tapes and books when she first entered the hospital saying, "You may not need these right now, but maybe in the future."

"Three weeks later, bored, I turned these tapes on," Lisa said, "and they helped immensely. Learning the technique got me through some really hard times."

Through these tapes she whisked herself off to Buck Island in the Caribbean, a place she had gone four years previously with a group of co-workers. It took awhile to master the skill, but once she got comfortable with mentally going there she put her husband Dave into the picture. They lazed in the sun, floated in the crystal blue water, drank, ate and had fun. They went on a catamaran to an underwater provincial park, exploring beautiful fish and coral reefs. She spent hours there in her mind, away from the reality of her life. Then as a surprise, for her fortieth birthday, Dave took her off to Buck Island and together they relived her fantasy.

Lisa doesn't take her recovery for granted. She knows it took a community to help keep her alive. To celebrate her life she threw a party to mark her third year anniversary. Her elegant roomy house was packed with people from all stages of her life, including her hematologist. She threw another party to celebrate her ten year anniversary to thank everyone who participated in her success. There were over one hundred people. The air was alive with her humility and appreciation. It was a happy occasion.

To give back to society for her gift of life, Lisa volunteered at the Leukemia Research Fund, eventually becoming the President. She also worked for 5 years at the Canadian Cancer Society (CCS), managing the Diamond Ball Gala. She is a living example of the CCS's company motto – Cancer can be beaten!

Janey's Story

Janey was diagnosed with acute lymphoblastic leukemia (ALL) in 2002

BEFORE my diagnosis with cancer, I had been working less than a year in my new career as a registered massage therapist. After conquering a serious phobia, I had learned how to drive at the age of 38. My husband and I had recently bought a house and were attempting to have our first child. We had been fortunate enough to travel some of the world. Life seemed to be unfolding exactly how we had envisioned it.

Exactly one year after 9-11, I was diagnosed with acute lymphoblastic leukemia (ALL). I was not shocked that I had cancer by the time that day came but I was confused by the type. I had known from ultrasound results that I had lesions on my liver so I had already suspected the worst-case scenario. However, in the wee hours of the morning, when the Emergency resident finally told me it was leukemia, I was definitely taken aback. I thought, "Wasn't that a childhood disease that I had seen on TV telethons?" It took awhile to process the information and I had time alone to wait until a few hours later to tell my husband, Karl. I quietly whispered to him that our worst fear had come true. The dreaded "C" word was said.

The treatment protocol for ALL takes an extremely long time so my new career came to a grinding halt to undergo chemotherapy and cranial radiation. Treatment became my new full-time job. I spent my time hospitalized or receiving chemo or radiation at outpatient clinics. After each bout of chemo I developed a complication so I was hospitalized each time. My social life was interacting with fellow patients or the hospital staff. Everyone who worked at each of those three hospitals was absolutely wonderful. Surely they are all angels here on earth sent to make our lives a little easier.

My friends and family visited and /or telephoned me often, which was one of the fringe benefits of not working. I joked that I had always wanted to live in my pyjamas with plenty of time to read or listen to music. My husband worked to pay the mortgage and bills and keep the house while I contributed my paltry CPP disability cheques. I felt useless but not guilty that I could not equally contribute or help at home. I had had my turn at supporting us when my husband had a serious illness back in 1993. We had learned what "in sickness and in health" truly means in marriage vows.

My husband and I are even closer than ever since this experience. All of my relationships with family and friends have deepened and intensified in my life. I share my feelings about people more easily. I hug more, kiss more and think about others a lot more. I rarely used to cry. Now, I allow myself the catharsis to cry with tears of sadness or joy. I used to be a shy person. Now, I take more risks. I had been afraid to truly live

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and this diagnosis enabled me to try new things or things that I had feared. Our time on earth is precious and I am not going to waste it anymore being afraid.

Strangely, I did not fear death, only the separation from my husband. I have seen many people succumb to cancer especially to leukemia. One day they are sitting beside you, the next they are gone in what seems like a blink of an eye. Being a cancer survivor means that I now have a mission here on earth because I was one of the few left behind... a mission to be the best human being that I can be, to act in a way that gives meaning to my life, to share compassionate love with all those that I meet, and to not let fear stop me from doing the things I have always wanted to do.

During my illness I had endured pain I never knew existed. Although I prefer not to feel pain, when I do, I am grateful. Pain is a warning system. It tells you that there is something wrong in your mind and/or body that you should not ignore. Without pain, we cannot protect and care for ourselves. The most difficult challenge about having cancer is not the pain that you feel or the terrifyingly invasive treatments, it's looking into the eyes of your loved ones who are mentally tortured and who feel helpless because they can only watch you endure it.

After learning of my remission, another challenge was the constant anxiety about relapse. It began with daily thoughts for a long time but over time has lessened. However there are still things that can trigger these thoughts. A child in a newspaper in need of a bone marrow donor, an ad for a run for cancer, a check-up at the hematologist, opening blood test results, and the list goes on. These all bring to mind there is always a chance for relapse. However, they no longer upset me. Rather, they help me to focus on my loved ones and on living life in the present moment as much as possible.

My husband, my friends, my siblings, and my colleagues have been very supportive and loving of me right from the start. I think everyone I know was shocked at first. I was the person who didn't smoke or have a microwave, who avoided artificial sweeteners, who tried to eat healthy, who took vitamins... At first, no one wanted to hear my thoughts and feelings about dying. Everyone desperately wanted to believe I would survive. I had friends, family and congregations in churches and Buddhist monks all

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The most difficult challenge about having cancer is not the pain, it's looking into the eyes of your loved ones who are mentally tortured and who feel helpless because they can only watch you endure it.

praying or meditating for me. The support was overwhelmingly humbling. Initially many people visited me day and night. I was truly fortunate and I actually had a lot of fun when I wasn't in pain. Laughter really was the best medicine.

My elderly neighbours were upset about the bad news but I think they are more philosophical about life being in their 90s. They have seen many people come into this world and many leave at all different ages. One would assume that someone nearing the end of his or her life would find a cancer diagnosis easier to accept, having lived a long life but this isn't always a rule of thumb. When you are in the early years of life I would think you would think having cancer is incredibly unfair. You may never experience the wonders of the different stages of life. However, sometimes youth is far more accepting and adaptive. In mid-life when I was diagnosed, I had not had the joyous experience of my own child but I had spent many wonderful years with my soul mate that I met at the age of four. I think the perspective may be different for different ages but the feelings are probably the same. Depending on age and personality, men may not show as much emotion in their personal reactions. However, that does not seem to hold as true during this age of Metrosexual Men. It is painful for anyone to think of the physical separation from loved ones. Cancer seems to break down the seemingly most impenetrable of emotional walls.

The hardest thing for me was letting go of my vision of my Life. We all expect our lives to travel a certain path – you are born, you grow up, get a good job, buy a house, travel, have your own family, retire, grow old and finally die. When I had to let go of the vision that possibly my soul mate and I would be separated in mid-life, I was very reluctant to do that. Meditation helped me to find peace by gaining the knowledge that we can never be separated even though our physical bodies will die. Our souls are eternally connected. The essence of every sentient being will be reunited in what I call the Next Dimension. I no longer fear the loss anymore. This is a tremendous comfort to me, which brings me the peace to accept death



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at any age. However, to be honest, my Ego still dreads that physical separation when it comes.

Since my cancer diagnosis, the sun shines a little brighter, the grass is a little greener, and the flowers smell a little sweeter. I literally stop very often to smell the roses. Everything on Earth is truly a wonder of the World. So, what I have learned since I got cancer is that one must start to live the Life one has always envisioned immediately – right this moment. There are

many wise people throughout the ages who have imparted similar insights in such sayings as “Carpe Diem!”, “Nothing is more important than this day”, “The power of Now”, and “Don’t wait. The time will never be just right.”

My personal favourite is a wonderful Tibetan proverb – “It is better to live one day as a tiger, than a thousand years as a sheep.”

Before cancer I was consumed with fear and in a sense embraced Death. Now I have fully embraced Life.

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Mandy's Story

Mandy Atwal was diagnosed with acute promyelocytic leukemia (a sub-type of AML) in 2003

My name is Mandy. I am not a patient. I am not a statistic. I am a survivor. Living proof that miracles do happen.

Being a healthy, active 24-year-old with lots of life to live, I would have never imagined that I would be hit with such a devastating illness. At the time, my worries in life ranged from small things, such as what colour I was going to put in my hair, to the biggest thing being school assignment deadlines. My range of worries was quickly about to change.

On August 29, 2003, my world turned upside down. What I thought to be the biggest worries in my life soon became insignificant. I was called in to VGH for further investigation on my abnormal blood results, drawn earlier that day. The recipe to my diagnosis: start with a mini assessment; add a few more blood tests; throw in an Ativan and spike it with a dash of biopsy. My final result was leukemia.

Fortunately for me, the situation seemed hopeful. The physicians were ecstatic to tell me about my promising statistics. Being newly diagnosed and clueless about what this disease entailed, I accepted the statistics as if they were solely based on me. What could be better than hearing a doctor tell you that if there is any type of leukemia you would want to have, APL is the one. With such positive attitudes and reassuring numbers, I was sure that I would be out of there in no time to spend a weekend in Whistler before the summer was over. I spent the next 100 days in the hospital fighting for my life.

My family and I had a very hard time battling leukemia. We were fighting all kinds of complications due to the harsh side effects of the chemotherapy. We made such frequent trips to the OR and ICU that we deserved frequent flyer miles! Now, my worries ranged from small things, such as nausea and vomiting, to major things such as recurrent internal bleeding... quite the change from deciding on hair colours!

Things were starting to look pretty hopeless. On many occasions, the medical team gave up and we were told that saving my life was a hopeless task. But we never gave up hope... and God never gave up on me. When times got tough, we got tougher. My physical recovery was harsh and painful, but I believe that the hardest part of the disease is the mental anguish that accompanies it. Having to wake up every morning not knowing if I'm still in remission; staying up late at night having thoughts of whether or not the remission will last. Last but not least, asking that million dollar question: why me? And the worst thing about this question is that it remains unanswered.

My physical recovery was harsh and painful, but I believe that the hardest part of the disease is the mental anguish that accompanies it.

As I look back at my experience, I now believe that I am most fortunate. Of course, I did not always feel this way about being hospitalized. I must have been the angriest, most depressed, and frustrated patient on the ward. Any person of authority was immediately considered an enemy. I trusted very few, especially if their names began with 'doctor'. But then I came to a realization. I realized how fortunate I was to have had cancer. How can I say such a thing, you ask? This is because it is cancer that taught me how to live again. It is cancer that gave me the chance to face death and win. It is cancer that proved to me how amazing my support system really is. Finally, it is cancer that taught me that it takes strength to survive but it takes courage to live.

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Tom's Story

Tom Strodl was diagnosed with chronic myeloid leukemia (CML) in 1990

TOWARDS the end of June every year for the past thirteen, Tom had gone to a lodge at the northern end of the Queen Charlotte Islands with a group of old friends to “power fish”, and it was always a high point of his summer. He'd been feeling a little tired of late, which, at forty-eight years old, we laughingly referred to as his new speed. However, he did go in for a physical before he left.

He arrived home at the end of the week to find a message from our GP's office asking him to please call. By the time he was able to call, the office was closing for the weekend and the only one still there was the office nurse. She was so taken by surprise, she blurted out the fact that Tom had “missed his appointment at the Leukemia Clinic at UBC Hospital.” Realizing that Tom had absolutely no idea what she was talking about, she quickly made him an appointment for first thing Monday morning and wouldn't say more.

Needless to say we spent a very uneasy weekend trying to find out who this doctor was and what exactly his specialty was, to no avail. We arrived at our GP's office, having more or less convinced ourselves that this was some sort of a mix-up in the paperwork. Unfortunately we were very much mistaken. Our GP was off on maternity leave and this poor doctor whom we barely knew had the difficult task of telling us that Tom's lab work indicated CML and he needed to go to UBC for a bone marrow biopsy, as soon as an appointment could be rescheduled.

We sat in the office trying to absorb this information. This was the first time we heard that this was the “best” kind of leukemia to have, if you had to have leukemia, and other useful information. After a short time Tom excused himself to get some air and left the office. I stayed long enough to get scripts for anxiety and sleep, and was also told our GP had said to feel free to call her at home (which we did). The drive home was very quiet as we tried to get our brains around the idea that our very good life had just been changed forever.

In very short order we found ourselves at the UBC clinic for the first of many bone marrow biopsies. We were walked through the procedure by a very pleasant doctor who told Tom his bones were as tough as a bull elephant. For some strange reason we thought this was a good thing! This procedure, not to mention the several prescriptions we left clutching, made the reality of Tom's diagnosis undeniable.

The painful necessity of telling the families had arrived. We began with Tom's older sister, Bernice and her husband Manfred. This is not the kind of family that requires prior notice if you want to drop in, so they

The drive home was very quiet as we tried to get our brains around the idea that our very good life had just been changed forever.

Tom asked his only question of the meeting. He asked Dr. Barnett completely deadpan if he'd "be able to dance a jig after a BMT," to which Dr. Barnett replied equally deadpan "I don't know, can you dance a jig now?" and on that note the appointment was over.

were, I'm sure expecting some sort of news, but not the kind of bomb we dropped. After a moment of stunned silence, they immediately wanted to know how they could help. The next person Tom wanted to see was his older brother Joe, and he wanted to talk to him by himself. They met the following morning at their favourite breakfast spot and once again the disbelief was quickly followed by offers of help. This same scenario was repeated, again and again, as we shared this difficult news with the people closest to us. We couldn't have asked for better support!

The next step was an appointment at Vancouver Hospital with one of the doctors on the BMT team. At that time the Outpatient Clinic was a rather dreary place in Heather Pavilion, a place with which we would, in time, become very familiar. Bernice came with us for moral support. And there we met Dr. Barnett. As he gently presented all the treatment options available to CML patients, with all their intrinsic pros and cons, it became very clear that this was a decision only Tom could make. After a few questions by Bernice and me, Tom asked his only question of the meeting. He asked Dr. Barnett completely deadpan if he'd "be able to dance a jig after a BMT," to which Dr. Barnett replied equally deadpan "I don't know, can you dance a jig now?" and on that note the appointment was over.

Tom has had a very full and successful life and has always believed his hard work was liberally blessed with good luck. He travelled to thirty-eight countries in the freewheeling sixties, and had the time of his life, a year he wouldn't trade for anything. Tom and I had been married for twenty years by the time of his diagnosis. I watched him design and build (quite literally) the home we still live in, while developing and successfully operating several businesses. We were able to travel together, he bought the boat he had always wanted, and we had some wonderful times with friends sailing the BC coastal waters. He worked, played tennis, gardened, cooked, fished and sailed with equal enthusiasm, and we had and still have wonderful friends to play with. So when Tom said he'd had a great life, with no regrets, and he was going to take his chances with a transplant, I can't say I was in the least surprised. Tom's approach to life has always been straight forward, even in situations like this.

Once the decision had been made the search for a marrow donor was on, which of course started with his two siblings. The chemo drugs were making him feel lousy, something he'd never had to deal with to any extent before, combined with the waiting around for testing results were making life quite strained around our place. I do have an unfortunate tendency to hover when I'm worried, which makes Tom crazy, hence we were both just a wee tad testy!!



The chemo drugs were making him feel lousy. Combined with the waiting around for testing results, this made life quite strained around our place.

Tom and his closest friend, Ron, spent countless hours together just walking and talking, giving Tom the chance he needed to vent about all the things he didn't want to talk about with me. One of Ron's passions in life is flying his little red CB, and he has invited Tom to come with him for years. Typical of Tom, he decided he had nothing to lose, and may never have another opportunity, so he decided to go flying.

On a beautiful September afternoon as Tom and Ron were soaring over Harrison Lake. I got the call with the testing results. Bernice was a perfect match. I called Ron and gave him our wonderful news and he said, "just hold on a minute, I think I'll take the controls back before you tell him!" They put down on the lake and shared a coke and a cry, and Ron threatened to put him on a bus for home, because "if anything happens to you now Chris will have my head". It was one of the best days of our lives. At the time we really didn't realize how truly lucky we were to find a donor so quickly, but we certainly do now!

Now came the wait for a bed to open up on the BMT unit. At the time the liaison for the unit was a terrific lady, Marion, who always seemed to be available with encouragement, information, or whatever was needed at the time, like meeting us in the Emergency Department when Tom had a battery blow-up in his face or when he lacerated his skull on the bottom of his boat, and several other occasions I won't bother mentioning. During this time she shepherded us through our tour of the BMT unit, and introduced us to some of the support staff, including the social worker, the dietician and the physiotherapist. We were very fortunate to be able to live at home and to not have the financial and job related problems so many other families had to cope with along with leukemia. For us, waiting for a bed was the most difficult time to get through.

We still spent time with friends and family, but the effects of Tom's chemo tired him and made him much less interested in socializing. We also felt we needed to "get our affairs in order" both at home and at the business, and these tasks forced us to deal with the possibility of an unsuccessful outcome. It often took more energy than we had available and left us both drained. I never allowed myself to believe the worst could happen. However Tom's approach was to assume what would be would be and to not waste time dwelling on it. Tom, being a kind of take-charge guy, found his lack of control a new and frustrating sensation. Our frequent trips back and forth to the hospital lab for blood chemistry monitoring seemed to consume our days.



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Then THE call came. We had a date and a bed! The transition from outpatient to admission happened very quickly! Suddenly we found ourselves in the room that would be Tom's entire world for the next thirty-eight days. The isolation units were a typical private hospital room – bed, bathroom, chair, bedside chest, a tiny cupboard, table/tray, window to the outside, and a heavy door with a window which looked into the enclosed isolation corridor. It was accessorized with a TV/VCR, a telephone, and a large blackboard with a chart to track days, drugs, and blood counts.

Patients were encouraged to personalize their space with things such as comforters, their own pyjamas, and whatever else they wanted to brighten up their space. We arrived with bedding, pyjamas, toiletries and a fishing rod. Tom knew he wouldn't want to spend his days looking at blood counts so I found an assortment of travel posters to cover the board. As time passed, a giant painting from my sister and her family in Victoria was added. On it were hand prints, sunshine, a boat, the dog, the cat, flowers, self-portraits, and some things which were subject to interpretation. It was visible from the corridor and always elicited big grins from passers-by. In short order two poster sized collages of friends and family added to the wall adornments. Tom's sister contributed a huge tin of wonderful homemade cookies, which prompted the notation at the nurses' station "great cookies in Tom Strodl's room". As Christmas approached his buddy Ron contributed a rather bawdy Rudolph complete with a flashing red nose, and with the addition of the best silk flowers we'd ever seen, the décor was as far from Hospital as we could make it.

Things began a bit shakily, with problems getting his Hickman® line inserted, first due to lack of OR time and then because they were unable to use the preferred three lumen unit, which complicates the way the drugs and blood products can be given. As the chemotherapy progressed all the things we had been told to expect began to happen – hair falling out (which fazed Tom not at all), the exhaustion, and of course, constant nausea.

Prior to Tom's admission, he was put in touch with a former BMT patient whose situation was similar to his own, and one thing he had told Tom was to force himself to eat, and to try to stay off the IV food bag. Tom was so determined to stay off the bag that when I arrived, usually around ten, he would still be struggling to get through a small box of cereal, one flake at a time. The food situation was difficult for us both. Frequently just the smell of his food tray was enough to make him sick and so was immediately banished to the hall. I tried to keep him eating by bringing smoothies and his favourite foods from home. He'd think





he wanted something specific to eat and when I arrived with it even just the smell of it made him feel just as awful as his hospital tray had, which was very discouraging for both of us. But nevertheless he managed to choke down enough nourishment to keep him off “the bag”.

Then one awful night Tom said he felt wet and thought his IV might have pulled out. However a quick look revealed it was his Hickman® line that had come out and was spurting what seemed to us like gallons of blood everywhere. An emergency 1:00 am trip to the OR provided a new Hickman® line, and, on the plus side, this time they were able to get a triple lumen in!

Most days were filled with a lot of sleeping, punctuated by bouts of nausea, and an occasional video that we seldom watched to the finish. We both thought laughing was one of Nature’s great healers, and so of course that was our taste in films. As we got to know the doctors and nurses better, some brightened his day significantly more than others. In particular Tom credits Dr. Nantel and his kindred sense of humour with making his days more bearable. He looked forward to his jokes and attempted to keep up his end by having one ready for him. This relationship continues even now, through some tough times for both of them. Without a doubt just knowing Dr. Nantel was out there definitely gave us a feeling of security! Tom’s primary nurse, Jackie, was also a willing co-conspirator in the various pranks that broke up the tedium of those long days.

Tom had decided before he went into the hospital he was going to keep as fit as he possibly could while he was there, so he requested a stationary bike from the physiotherapist. With very few exceptions he dragged himself onto it even if it was only for a few minutes! The small victories become huge under these circumstances. Tom really didn’t want visitors, partially because we were so aware of how non-existent his immune system was and because he simply didn’t have the energy to deal with company. Reading was even too much to concentrate on as his counts got down toward ground zero.

When the time finally arrived for his sister to have her bone marrow harvested, it was very strange for Tom to think of her lying several floors up, trying to save his life. At this point in the process Tom was taking it hour by hour, and although he had transfusions of various blood products, blood still made him feel squeamish. When the time for

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the actual transplant arrived and the freshly cleaned marrow was ready to be dripped in, Tom wasn't at all sure he wanted to watch the process. His ever resourceful nurses once again to the rescue created a very silly bunny mask out of a brown bag and odds and ends and voilà, no more bag of marrow. It was still a very tense time for such a low-key procedure but without a doubt it helped. We still have the bunny!

Now began the really scary part – would Tom's body accept the marrow and start to rebuild or not. Fortunately Tom has very little recollection of the days following November 26th. He was aware at the time of the daily tally of his blood counts, but the unpleasant side effects of the chemo continued to be accompanied by mouth ulcers which required a truly awful brew to treat. Tom kept telling me I really should try it so I could appreciate how truly nasty it was; however the look on his face was quite convincing enough. At this point it was just a matter of waiting, and waiting and waiting as the blood counts bounced around.

A week or so into December, Tom's counts were creeping up steadily enough for a trial trip away from the hospital. We were going to take a drive. It was a cold sunny day with snow on the ground when Tom's brother and I set off with Tom bundled up to the nose. We thought a drive through Stanley Park might be pleasant, and we had almost made it to the park, when Tom's anxiety level indicated it was time to go back. In truth, Joe and I weren't in a much better state. I'm still not sure exactly what disaster was likely to befall us, but we were all quite relieved to get Tom back into his cocoon unscathed!

It was just days after our outing that discharge began being mentioned. Although you leave the hospital, the need for a Hickman[®] line is by no means over, but having capable nurses to care for it is. When his nurse appeared in the room with two large bags of supplies and a bright smile saying “this will be a breeze, but it's very important to get it right,” Tom's heart sank. I was allowed to look but not touch. It was made very clear this was Tom's responsibility regardless of my offer to take it on. In very short order it became a routine part of every day, but to begin with it seemed very daunting.

Discharge was becoming a very real prospect and I arranged to have everything scrubbed from top to bottom, despite being told it wasn't really necessary. The morning of December 24th Tom called to tell me that he had been discharged and would be ready to go. Totally unprepared, with nothing to eat in the house and still slightly damp carpets, I cranked up the heat, which had been turned down to dead low because I was never home, called Bernice and asked her to pick up Tom, changed the sheets on the bed and raced to the grocery store. Because it was Christmas Eve, a twenty minute shopping trip wound up taking over an hour. I managed to arrive home a mere five minutes before Bernice and Manfred arrived with a very shaky Tom in tow. They opted not to come in, feeling Tom would prefer to have some alone time. They deposited

all our “stuff” from the hospital, several large bags of Hickman® line maintenance supplies and Tom in the front hall, handed me a fistful of paper work, and with offers to help anytime, departed. We stood in the hall looking at each other and promptly started to cry. Welcome home!

After getting Tom settled as comfortably as possible, it was time to get the prescriptions filled. I wasn’t happy about leaving Tom alone but it couldn’t be helped. Our home had absolutely nothing festive about it that year, but having Tom made that Christmas wonderful!

The schedule of appointments began a few days later. We were instructed to be at the Outpatient Daycare at 8:00 am every Monday, Wednesday, and Friday for blood work, weight and vital signs monitoring. The early hour was necessary in the event that a transfusion might be required, which was not an uncommon event. We were often there anywhere from an hour to three or four on any given day. The weather that winter was brutal and our forty minute commute back and forth often became much longer. If you’re going to have a BMT I highly recommend the spring time! This regimen was completely draining for both of us. We’d leave home in the dark, drop-off any new prescriptions on the way back, and arrive home in the dark. While Tom collapsed into bed, I’d head back to the pharmacy to pick up the new meds.

Tom (and in fact his entire family) has a thing about taking pills. At times he had up to forty pills daily in his drug cocktail, and he hated it with a vengeance! My attempts to sell them as the “troops” in his arsenal to fight graft-versus-host disease etc. were not received with particularly good grace! He went from a guy who could hardly swallow an aspirin with a full glass of water to being to able to get several pills down without the benefit of liquids! Many of the drugs had pretty awful side effects, and when I come across any of the few pictures of those days Tom is barely recognizable.

By this time Tom had developed the typical mouth sores caused by graft-versus-host disease. Between that and the ongoing stomach problems caused by drug side effects, feeding him was a challenge. We relied heavily on smoothies. In fact, I would fill a large thermos at bedtime for him to have during the night.

There were the inevitable GI problems, aching joints, muscle spasms and some excruciating leg pains that Dr. Nantel could never get to the bottom of. One benefit of BMT, if you can think of it that way, is getting in to see all the “Cadillac” specialists without any wait time. We can’t recall the order

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or what necessitated some of the appointments (memory can be kind) but we are now quite familiar with Gastroenterology, Dermatology, the Moveable Joint Clinic, the Dental Clinic at the Cancer Agency, the Respiriology Clinic, Neurology and all its attendant labs, and a vast assortment of other testing clinics too numerous to mention. Visiting outpatient clinics, specialists, dealing with his Hickman® line (which took some time due to lack of energy) and dealing with the bare essentials of life, took everything Tom had.

We had lots of people wanting to visit but with full blown flu season combined with zero energy, we stayed pretty much to ourselves. Our only socializing, if you could call it that, happened at the Outpatient Daycare. We got to know some other patients and their stories. It was there we began to appreciate just how fortunate we had been throughout the whole process. We met people who had never found a donor and had been forced to use their own treated marrow, patients who were rejecting their transplants, patients whose livers, kidneys, or other organs had been compromised by their chemo, others who were going through a second transplant, or whose families lived far away. The BMT team did a great job of supporting these people, but we quickly realized how very lucky we were to live at home, not have money worries, and be close to our family etc.

The day Dr. Nantel decided it was time to take out Tom's Hickman® line was a symbolic one for us. A big tether to the hospital had been severed, and in Dr. Nantel's opinion, Tom had reached a point in his recovery where re-hospitalization seemed unlikely. Hurrah!

Around this time, our leash to the Outpatient Daycare was also lengthened, and our regular schedule was cut back to weekly and then monthly. To this point I was always the driver, but the better Tom got physically the worse driver I apparently became. Tom's driver's license had expired so we got that renewed, just in case. The day Dr. Nantel told Tom he didn't want to see him for three months was the day he repossessed his car keys! I keep that "lovely" driver's license handy on the fridge in case we start to feel sorry for ourselves.

We now see Dr. Nantel once a year, and have been getting "normal" reports for quite a few years now. Never being one to dwell upon unpleasant possibilities, Tom doesn't expend any energy worrying about a recurrence of his cancer. It's something he can't control now any more than he could control its onset.

Post transplant, our biggest scare came when very stressed out friends we had spent the weekend boating with called to tell us that their son had developed chicken pox. The status of Tom's immunity to this disease was very much in question. He didn't know if he had had it, Bernice didn't know if she had had it, and

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if in fact she had, would her immunity have transferred with her marrow. The next thing we knew we were in Emergency, where Dr. Nantel held his hand while some blood product, rushed over from the Red Cross was dripped in. Suffice to say no poxes appeared, but we felt we had been very lucky to dodge the bullet.

It's been eighteen years since Tom had his transplant. In spite of requiring a hip replaced and ongoing medication to make up for a non-functioning thyroid gland, he is doing well. He still suffers with quite significant pain in his back, leg, and wrist, but has put off further surgical intervention for as long as possible. He takes as little pain medication as he can manage and carries on. He has never fully recovered

all the energy he used to have, but pushes himself to do the things he loves. He has an excellent business manager and a good staff backing him up, thus enabling Tom to step back and become for the most part an overseer. He still plays golf, it's become his new passion, cooks, fishes a little, gardens, travels (south!!) and has taken up bee keeping, managing to keep his favourite people in honey. In other words, he keeps as busy as his energy and pain will allow.

As soon as Tom was up to it, we went to a fundraising event for leukemia in our neighbourhood. Someone suggested to Tom that if he was interested in getting involved he might want to come to a Leukemia Research Fund meeting. He decided to go and see how things were handled. At the time the Leukemia Research Fund was in chaos, with directors resigning, people quitting right and left and events pulling out. How the donations were being spent was the big issue. A little golf tournament in memory of Sharon O'Brien was one of those events pulling out. This of course left their committee with no meeting space. Tom asked if it would be okay if they met at our house for a "little while". Because we have the space (we do), we are central (we are) and it would just be until they found another space (it wasn't).

Many meetings and bottles of wine later, this dedicated, hard working little group formed itself into an independent 100% volunteer driven charity called "Believe" and has carried on the tournament to

At times he had up to forty pills daily in his drug cocktail, and he hated it with a vengeance! He went from a guy who could hardly swallow an aspirin with a full glass of water to being to able to get several pills down without the benefit of liquids!

its eighteenth year. For a man used to being in charge, a committee was new territory. We are now the official address, phone number, and meeting place for the group and more than happy to do it. Tom spends countless hours on “Believe” business every year, and gets great satisfaction helping raise more donations every year. “Believe” has recently designed and funded a respite area on the L/BMT Inpatient Unit for patients and their families to use to get away from the “hospital” feeling and Tom was very involved in this project too. It all gives governing by committee an entirely new meaning!

We’re packing, anxious to get away from the rain for a couple of weeks, and we’ll be anxious to be home again to see spring arrive and go out into the garden. The primary change in life after BMT seems to be in velocity. Tom still does all the things he loves but now has a far greater appreciation of doing them. He has

always enjoyed “smelling the roses” but now he takes more

time to do it, without the pressure of feeling he

ought to be “doing something”. These days a

little bit of doing nothing, sitting in the sun

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It’s been 18 years since Tom had his transplant. The primary change in life after BMT seems to be in velocity. He has never fully recovered all the energy he used to have, but he pushes himself to do the things he loves. These days, a little bit of doing nothing, sitting in the sun reading, or just taking nap guilt-free is okay, and with some more luck, he’ll keep right on doing it for the foreseeable future.

Gerry's Story

Gerry Pinder was diagnosed with chronic myeloid leukemia (CML) in 2002

I was diagnosed with leukemia in September of 2002 and I was 50 years old at the time. I had a very active, full life with my wife and two teenage boys. My initial feeling was that the life we all enjoyed and had become accustomed to was about to end. The truth of the matter was that we all feared the worst. The hardest thing was worrying what my wife and children would have to go through should I not survive. I made up my mind that I could beat this disease with positive thinking and complete trust in my transplant team. My family would not be without me.

Upon meeting with the specialists and social workers, we soon realized that we would be given all the support and medical treatment that we needed to get through this challenge. We also realized that all of our family and close friends were there for us in any way that we needed. This gave all of us a huge amount of determination. We decided, as a family, that we could remain positive through it all and look back on this experience one day as just an obstacle we had to face.

When it came time for me to have my bone marrow transplant (my younger brother was my donor), my wife and I decided that we needed to remain together and therefore she stayed in my room with me and slept on a recliner for the duration. This at least gave us a touch of normalcy and allowed us to draw the strength we needed from each other.

I also decided to wear my own shorts and sleeveless shirts instead of hospital gowns. My wife cut the shoulder seams and rejoined them with snaps so that there was no interference with my Hickman® line. I was definitely more comfortable.

During my treatment, any discomfort and pain that I experienced was addressed so quickly that it was kept to a minimum. It is very important to communicate pain and discomfort right away so that your team can treat it immediately.

One of the side effects that I experienced was that all food and drink tasted like metal. I found that the only foods that

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I could taste were ice-cream and cooked pudding. The only beverage that tasted normal to me was Root Beer pop. I'm sure everyone is different but because eating is so important at this time, I thought I would share this tid bit. On a positive note, this wears off and you will enjoy your favorite foods again.

The one thing that being diagnosed with cancer has taught me is to appreciate everything that you do have and don't waste time worrying about the things that you don't have. Never "sweat the small stuff" and always be positive and plan your future.

Being a Cancer Survivor has given me the opportunity to see my two sons enter into the occupations of Professional Firefighter and Paramedic EMT and celebrate with them their accomplishments. I would not have missed this for the world.

It has been six years since my bone marrow transplant and my life is terrific. The only change I have made is that I don't push myself as hard physically.

Occasionally I think about recurrence, but as every year goes by I think about it less and less. I attend the Bone Marrow Transplant Clinic once a year now and I continue to have faith and confidence in their ability to monitor my health.

This experience has made us all realize just how quickly your life can be changed and how important it is to be positive and fight for the strength to survive. It works for us.

I and my family are so grateful to be able to put this all behind us. We have all made up our minds not to dwell on what we went through, but to dwell on what we have yet to do.

Remember, there is life after cancer and only you can decide what that life will be.

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Lymphoma

Stories



**Leukemia / Bone Marrow Transplant (BMT)
Program of British Columbia**

Sonja's Story

Sonja Braddock was diagnosed with non-Hodgkin's lymphoma in 2001

WHAT a week-end! Beautiful weather, excellent camping, surrounded by friends and doing something I love. Playing softball... 1st annual Sunshine Coast Tournament this week-end and WOW, we're in the finals!! Three straight games to Victory... WE WON!!

I'm glad, I don't think I could have caught another inning.

It's September and my 39th birthday is a couple of weeks away. Started my new job in June, training Director for Toys R Us. Finally after all those years of hard work, I'd finally made it to the top. My dream job.

Then it's Thanksgiving already, American Thanksgiving that is... had a marvelous day, good food, good company and lots of laughs. I went to bed feeling very blessed. Then it's 3 am... OH MY GOD, why am I in so much pain? I slide out of bed and stagger to the kitchen. HOLY MOLY, what could be wrong? A pinched nerve maybe? I've never felt such intense pain before. I think I'm going to pass out. The walk-in clinic opens at 9 am. The doctor confirms, it's Sciatica. Sent on my way with a handful of pills and a referral to see the Chiropractor down the street.

The next morning I get the same wake up call, this time worse. This isn't right I thought – something is wrong. I called my GP, she had me come in to see her right away. Five minutes into the exam, she was on the phone to the ER at VGH. The spine specialist was waiting for me to get there.

Eight hours later, specialist after specialist, test after test and morphine shot after morphine shot, they admitted me.

I believe I was nearing the 12th day in, I barely remember I was on such heavy morphine. It's around 10 pm when the neurologist walked in. She stood at the end of my bed and told me the results of my bone scan. She said they were 99.99% sure it wasn't cancer. That's GREAT I thought, but what a shock it was to hear those words, since I had no clue they even were suspecting cancer.

The next morning I moved to the 3rd floor, the Neurology ward. It was December 10th around noon when Dr. Sreenivasan from Hematology walked in. She sat on the end of my bed, I knew then it was something bad. That day would change my life forever!

I'll never forget those words, Sonja you have cancer. Non-Hodgkin Follicular Lymphoma. And I was already

I don't think I could have taken another round. Now, will I stay in remission?

1-2-3-5 ½ months passed, so far so good. Then I heard those words ring out again, it's back Sonja. We'll start chemo again, a different protocol this time.

in stage 4. HOW...? WHY...? BUT THEY SAID... OH MY GOD!!! What do I do now? I want my sisters... Why did I move so far away? I want my mom!!! But I knew that was impossible since I had lost her just four years earlier to cancer.

Tests more tests and more tests. They needed a biopsy to determine its grade... cancer comes in grades??????

December 15th, 7:00 pm... Hey, the operating room really does look like it is on TV. I opened my eyes... Where am I...? What's going on...? Where's Sherrie? My partner and primary caregiver. It's 3 am and that simple biopsy had gone terribly wrong. I almost died they told me. A routine laparoscopy had turned into an emergency surgery from stem to stern. This just isn't happening!!!!

It's Christmas Eve about 4:00 pm, they just came in and told me I could go home. I'm SO excited. My poor little pups, I left them the morning of November 27th and never came back. I had to recover from the surgery now before they could start with the chemotherapy.

January 14th, I'm ready, NO I'm not, and OK yes I am, like I really have a choice in the matter. It's NOT chemo, it's NOT chemo... it's sugar water, it's sugar water I kept telling myself. I'm laying on my couch... OH GOD I just want to die!!!! I can't do this anymore. This stuff is killing me. My test results came back today, I'm in remission. THANK GOD, I don't think I could have taken another round. Now, will I stay in remission?

1-2-3-5 ½ months passed, so far so good. Then I heard those words ring out again, it's back Sonja. We'll start chemo again, a different protocol this time, Fluridarabine.

I had big plans so it had to work!

It's early February, Sherrie and three dear friends loaded me up and drove me to Whistler/Blackcomb... certainly without my doctor's knowledge. I had a mountain to climb!!! I WOULD stand high atop that mountain, one more time! It meant as much to me to climb that mountain again as it did for the four other friends I had in my life. These friends were all patients and we had befriended each other through the web discussion boards at the Lymphoma/Leukemia site. We called ourselves "The Union of Hope". We were from all corners of North America. I



couldn't imagine going through this without them being a huge part of my life, then and still today.

So bundled up and boarded up, here we go slow and steady until we reached the top.

7th Heaven it was called. I thought how fitting! There I stood at 7,000 feet, with my arms held high, pointing to the heavens, shouting I DID IT! I DID IT!

Three cycles in, I planned my trip home to Georgia. I was going home again if I died trying. I called it my "Tour De Cancer." It was also a mission to meet a few of my Union of Hope friends. Here we go, loaded with morphine, travel bag of chemo and doggies in tow, Sherrie, a very dear friend and I started my 8,000 mile journey home.

Three and a half weeks into the trip, I knew it was back. The pain gave it away, always had. I've got to get back to BC, I can do this!!! Upon returning, tests confirmed what I already knew. It wasn't working. So we tried another chemo. It shrunk things and that's when they told me I didn't have much of a chance of survival, the chemo wasn't working anymore. I needed a BMT...

I read, I cried, I prayed, I listened, I asked a lot of questions and I read some more.

I'd made my decision. To the shock of all the doctors, I turned down the transplant.

It didn't feel right inside, I just couldn't do it. I'd take my chances with chemo again, imagine that – actually choosing chemo!

More chemo again with little results, my time it seemed had run out. Dr. Sreenivasan switched chemos, and got a response. It was then she told me I might have another chance at a BMT, if I responded to a round of heavy artillery chemo. I thought to myself, my God there's heavier?? This was my only chance. It all hinged on my response, me passing all the tests required to withstand a BMT and of course finding a donor.

I definitely know someone was watching over me, I passed all the tests well enough, the cancer responded to the heavy chemo and a 10 point match was found. This time I was ready!

I didn't really have time to change my mind as it all happened so fast. Man, am I scared!!! They say I only have a 30% chance of surviving the transplant. Well that's not how I see it. When I make it, well that's 100%; without it I have 0%.

I set myself a goal. To be the first unrelated transplant patient in and out of hospital in record time.

I almost beat it! Twenty-six days later I walked out.

They
say I only
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that's not how I see
it. When I make it,
well that's 100%;
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0%.

I'm not here to say this road was or is an easy one, neither prior, during or after transplant. I could paint a once upon a time story with a fairy tale ending but then I really wouldn't be telling you how it really is.

What I can do, is tell you how important your support system is going to be, you'll need help and a lot of it for a long time.

I can tell you to always Hope for the best and prepare for the worst.

I can tell you there will be days you'll think to yourself – "Was this the right decision?"

I can tell you months will pass that will be a blur to you.

I can tell you that walking around the block will be as big as finishing a marathon.

I can tell you that pills will be your breakfast, lunch and dinner.

I can tell you how fragile you will be and how dangerous simple things in life will be to you.

I can also tell you that in the end, you'll be glad you did it when you're able to see another sunset or get a hug or laugh out loud or gather together with friends or smell a flower or watch kids play or pet your animals or help someone else.

At the end of the day, you can only have hoped that maybe one doctor may have learned, one discovery may have been made, one life may have been spared, belief renewed, hope restored and faith laid to become a solid foundation, not only for yourself but for everyone around you. Knowing that your journey will have made a difference somewhere, somehow. Each night before I sleep I am thankful and content!

February 19th, 2004 was five years ago. Would I change a thing? NO! I can tell you my life has changed and it still changes.

But I feel lucky. My eyes open everyday and my feet hit the floor.

I may never play ball again, I may never climb another mountain, I may never drive another "Tour De Cancer." But I might!!!!!!

NEVER STOP BELIEVING.

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Multiple Myeloma

Stories



**Leukemia / Bone Marrow Transplant (BMT)
Program of British Columbia**

Keven's Story

Keven Drews was diagnosed with multiple myeloma (MM) in 2003

I remember the day I first began to fight back against cancer. More than a week after my diagnosis, in early April 2003, I was laying in a bed in Royal Columbian Hospital. Visitation hours were over. My parents and wife had left. The ward was quiet, and the room was dark. Days earlier, doctors had diagnosed me with multiple myeloma, a nasty blood cancer that had attacked my bones, wreaking havoc on my vertebrae. The disease usually attacks people in their 60s; I was just 30. So there I was, with earphone plugged into the TV, watching a Vietnam-era war movie. Then, out of nowhere a phrase popped into my head: "I ain't dead, yet." I repeated it, and for the first time in weeks, I cracked a grin. Who knows what lay ahead, I thought, but one thing was sure: I was still alive, watching a movie.

Throughout my treatment, at points when I was feeling the worst and sickest I've ever felt in my entire life, I'd repeat this phrase. I repeated it when I felt excruciating pain, feared for my own survival, faced my stem cell transplant, recovered, and, yes, relapsed.

In addition to my religious faith, this little phrase gave me a tiny sense of power after cancer had sent my life spinning out of control. "I ain't dead, yet" was a sentence, a weapon, a mantra I could hurl back at the face of cancer. However small a weapon it was in this great battle, it was still a weapon. And I used it.

My war against cancer officially began on March 31, 2003. Until that day, I was a journalist on the career path who was supporting a wife attending UBC. I was active, a former soldier, a surfer for nearly 17 years and a man who lived to run. But after months suffering through excruciating back pain – a pain diagnosed as a slipped disc, but a pain that felt as if somebody were twisting a dull screwdriver into my spine – I was admitted to Royal Columbian Hospital in New Westminster.

Within hours my doctor delivered the news. "You've got cancer." Immediately, I felt as if I was an actor in some movie in which I had no control over, a feeling that has followed me ever since.

My family – my wife, my parents and my brother – were all crushed.

"Terrified" is not a word that would do justice to how they or I felt. I'll admit when I wasn't drugged out on morphine, a drug that has controlled my ever-present pain ever since, I cried a little too.

After about two weeks I was discharged, and over the next three months as I waited for my stem cell transplant between April and June 2003, I relied on "I ain't dead, yet". I repeated it often during my transplant's workup, during radiation treatment and blood work. I repeated it many nights after my prayers.

Out of nowhere a phrase popped into my head:
"I ain't dead, yet."
This sentence was a weapon I could hurl back at the face of cancer.
And I used it.

I repeated it whenever I was terrified, a feeling that overwhelmed me as soon as I researched my disease on the internet and in pamphlets and brochures. Don't get me wrong: I'm not saying that family, friends, church, God, comedy, books, great nurses and doctors, and lots of luck didn't play a role in my emotional health and survival. They did and do, and you'll need to call on some or all of them to get through this battle. Yet, they were and are all external forces I've called upon. "I ain't dead, yet" was different. Like my faith, it was something internal I could call upon.

In early June 2003, I remember feeling terrified, yet a little relieved, as I walked onto VGH's Leukemia/Bone Marrow Transplant ward. Yes, I was finally being treated in a significant way, but this was it; this was the big life-and-death showdown. My first night on the ward, I remember sitting on a bed, talking to a doctor. "Well," she said, "you've certainly got a big battle on your hands." I didn't respond, but said silently, "I ain't dead, yet."

My wife soon joined my battle, posting on the walls more mantras: faith, hope, fight, fight, fight, and even kick ass. My parents and friends, even church leaders visited, lending me emotional and spiritual support. Every morning I awoke, however, I saw those mantras posted to the wall. I saw them while I was throwing up from chemo. I saw them as I waited for my counts to climb following my stem cell transplant. Those words joined my arsenal of weapons. With "I ain't dead, yet," they gave me a great psychological boost.

Somehow, I made it through the transplant, and in early July 2003 with a cane in one hand, I shuffled off the transplant ward.

Since my transplant, I've faced some tough times. It was stressful waiting for my 100-day checkup and my doctor's announcement that I was in remission. It sucked watching one friend, whom I'd met on the ward, die, and others stop attending the outpatient clinic as I continued to live and gain strength. I felt drained – as if a battery was sucking power from my body – during the onset of graft-versus-host disease in the Fall of 2003. Sometimes, I'd sleep for 16 hours a day. Yet, I continued to grow stronger and stronger until I relapsed in the Fall of 2005. Somehow,



some of my cells went haywire inside my skull's marrow and a tumour grew, taking out a toonie-sized chunk of bone. Once again, doctors hammered me with radiation and drugs, killing the tumour but leaving a huge hole in my head. My hematologist gave me the all-clear sign in December 2005. Looking back, "Hell" couldn't describe what I've faced in the last three years. Regardless of how sick or depressed I felt, however, time and again I'd just have to remember one thing to make myself feel better: "I ain't dead, yet."

My life has changed dramatically since March 2003. My career is no longer as important to me as it once was. Family, especially my wife, is now my priority. I have fewer friends now. Some, I believe, just couldn't watch me wither and possibly die. Faith is more important than ever. Don't forget the "God factor."

Today,
I live a
simple life. Yes,
there's a chance
I'll relapse again, but
that's not the case
right now. Right now I
can still enjoy life. Best
of all, I woke up this
morning to enjoy
it all again.

Today, I live a simple life. I run a small online newspaper in Tofino, B.C. I walk on the beach, read books and magazines, and when the surf is up, I pull on my wetsuit, grab my board and catch a couple of rides. Oh, yeah, I coat myself in sunscreen. Most important of all, I now focus on the moment. Yes, there's a chance I'll relapse again down the road – knock on wood – and face more treatment and, perhaps, a not-so-happy outcome. But that's not the case right now. Right now the sun's still shining, the birds are still chirping, and I can still enjoy life. Best of all, I woke up this morning to enjoy it all again. I have to say, "I ain't dead, yet."

Mission Speedway learning racing techniques. I did some traveling visiting relatives in England, New Zealand and Australia. On those trips I made

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wife soon
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Notes



A large, light-orange circle is centered on the page, serving as a background for a writing area. The circle is filled with a solid, light-orange color. Overlaid on this circle are horizontal lines, spaced evenly, for writing notes. The lines are thin and light gray, extending across the width of the circle. The word "Notes" is written in a large, orange, sans-serif font in the top left corner of the page, above the circle.

Francesca's Story

Francesca Plaster was diagnosed with multiple myeloma (MM) in 1995

IN October 1995, I was diagnosed with beginning stage of multiple myeloma: MGUS – a monoclonal gammopathy of an unspecified source. A mouthful of words to be sure.

To the date of writing this, I am still being monitored by regular blood work, skeletal surveys and bone marrow biopsies. My health remains stable and I live an active and rather busy life.

In 2003 the decision to form a support group for multiple myeloma patients, their families and caregivers became a reality. It has been the most rewarding time of my life.

I have had the opportunity to follow people through their diagnosis, pre-treatment, stem cell transplant and a return to the daily routine of life. The need for the group and the services provided have proven to be a great source of support and strength to all of those individuals who come to the meetings. I will be forever grateful to all of those patients whose positive attitudes and strong desire to survive have enriched my life.

My story is not really one of survival but one of hope. I have lived with this condition for a lot of years and through those years have seen many great breakthroughs. Along with the improved stem cell transplant procedures (stem cell transplants can now be done as an outpatient, totally unheard of just a few years ago!), many new drug therapies are now in use to ensure longer survival rates.

It is my most sincere hope that multiple myeloma will soon be a chronic condition and not an acute one. A wonderful researcher once said that he believes that multiple myeloma will be something that people die with and not die from. This is also my hope for the very near future.

My life has been changed for the better as a result of this diagnosis. My outlook towards life and all it has to offer is much more sharpened as a result. I have lived with this condition for over ten years and it has given me a lot of time to evaluate the truly important things in life.

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time of my
life.

**My
story is
not really
one of
survival but
one of
hope.**

As you read this, may you be filled with my same hope and may you hold that hope close to your heart while you undergo treatment.

A wonderful researcher once said that he believes that multiple myeloma will be something that people die with and not from. This is also my hope for the very near future.

If you would like more information about Myeloma Vancouver, please ask the BMT social workers.



Updesh's Story

Updesh Nagpal was diagnosed with multiple myeloma (MM) in 2003

I am not sure if my story will be helpful for others but it is the one that gave me a will to set forth on the pilgrimage that I am on at this point.

I was diagnosed with multiple myeloma in December of 2003. This was not my first encounter with cancer. I had thyroid cancer when I was 24 years old and just newly married. My thyroid was partially removed and the rest was irradiated with radioactive iodine.

The second time the word cancer came into my life was after doing a routine PAP smear. There were some suspicious cells and I had a cone biopsy done. All was well though and I just keep going back for check ups.

This diagnosis came after about eight months of trying to find out what was causing my shifting bone pain.

I was 39 years old and had two daughters (11 and 9). With my husband's support, I was running a good business and being a very active full-time mom.

The day after the diagnosis I sat inside the car and prayed while my husband took out the girls to eat lunch. I asked for a sign to let me know if things would be okay. At that moment, a seagull flew down and sat on the hood of the car and looked at me. I shook my head and said that this was not the sign I was looking for. The bird flew away. Then a few moments later, in the middle of the day and the middle of December, a rainbow shone in the sky. This was my sign. I had never seen a rainbow in December in the Lower Mainland and I have lived here for over 25 years. I pointed out the rainbow to the girls and my husband. This is what gave me the will to go through the radiation, chemotherapy and the bone marrow transplant.

I guess I was one of the lucky ones to have a lot of support from my family and parents. They moved in temporarily to help take care of my children and me. My family and friends acted very positively. I had a lot of support, prayers from all different faiths and many phone calls.

In December, I underwent surgery to confirm my diagnosis. In January I had radiation. That was probably one of the lowest weeks of my life. I was in a lot of pain and suffered severe vomiting. Then I was put on medications (which I want to forget about) to prep my body for the onslaught of the chemo and the BMT.

I asked for a sign to let me know if things would be okay. At that moment, a seagull flew down and sat on the hood of the car and looked at me. I shook my head and said that this was not the sign I was looking for. Then a few moments later, in the middle of the day and the middle of December, a rainbow shone in the sky. This was my sign.

I am still suffering from some graft-versus-host disease but it is manageable now. I no longer have any bone pain.

Also, we had to start hunting for a match. Out of my two sisters, I was lucky that one was a match. She happened to be a medical doctor and my angel in disguise.

I had my transplant in April 2004 and five weeks later I was back in my own house. I spent the next 100 days waiting for the 100th day after my BMT. We all counted while going to the BMT Daycare and assumed that it was over after the 100th day.

Now it is two years after my first diagnosis. I am still taking cyclosporine two years post transplant and am looking forward to getting off of it. My pamidronate has been reduced to once in three months instead of monthly.

I am still suffering from some graft-versus-host disease but it is manageable now.

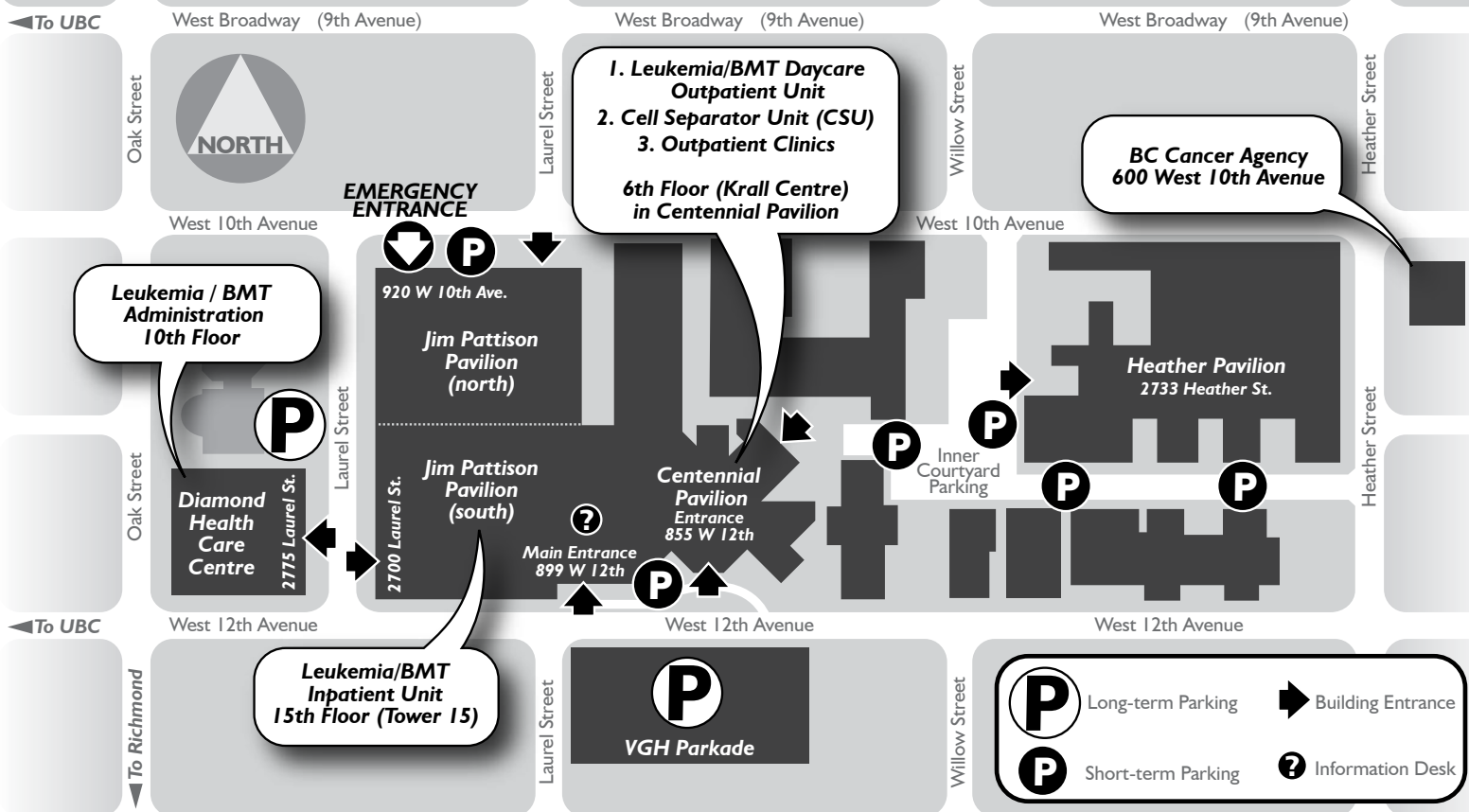
I no longer have any bone pain.

I take being a cancer survivor in a positive light. I treat the word cancer like any other disease, like diabetes, heart disease or high blood pressure. It is something I have to live with and manage carefully. It is something that I try not to fear and feel that there are many people working to find a cure. Yes I do think about a reoccurrence. I take life on a daily basis and enjoy every day as it comes. There are still good and bad days health wise but I take it in stride and am thankful that I am here to spend it with my family.

And I look for rainbows in the sky.



Leukemia / Bone Marrow Transplant Program at the Vancouver General Hospital



Leukemia/BMT Inpatient Unit (T15A)

Reception/Unit Clerk 604-875-4343

Leukemia/BMT Daycare Outpatient Unit (CP6 A/B)

Reception/Unit Clerk 604-875-4073 • After hours, call the Inpatient Unit 604-875-4343

Cell Separator Unit – CSU (CP6 C)

Reception 604-875-4962 • Booking Clerk 604-875-4626

After Hours call Locating and ask for the CSU nurse or doctor on call 604-875-5000

BMT Doctor (write your doctor's number in here) _____

BMT Coordinators

Branka Deutsch (unrelated)	604-875-4831
Carolyn Frew	604-875-4111, local 67486
Janet Bury (unrelated)	604-875-4111, local 67485
Mary Chan	604-875-4939
Sheila Wong	604-875-4111, local 63432
Valerie Campbell	604-875-4111, local 68549
Fax	604-875-5678 or 604-875-4910

Social Workers

T15 Inpatient Unit Office	604-875-4941
CP6 Daycare Outpatient Unit Office	604-875-4697

Pharmacist

604-875-4077

Occupational Therapist

604-875-4343

Nutritionist

604-875-4343

Physiotherapist

604-875-4343

Leukemia/BMT Program Administration Office

604-875-4863

Medical Services Plan of BC and Fair Pharmacare

604-683-7151 or 1-800-663-7100

Disclaimer:

Please note that the information contained in this manual is not intended to replace the advice of your health care team. Use this as a reference and education guide. Consult your health care team if you have any questions or concerns.



Leukemia / Bone Marrow Transplant (BMT) Program of British Columbia

Mailing Address:

Leukemia/BMT Program Administration
10th Floor, 2775 Laurel Street
Vancouver, BC
V5Z 1M9

Telephone:

604-875-4863

Web Site:

www.leukemiabmtprogram.com

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