

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

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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!!



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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

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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

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