

# Transplants Are Miracles In Progress

By Barry Butcher

The following is my experience and interpretation of how I believe we MUST continue to live our life to the fullest even with our unique form of Cancer - Multiple Myeloma. When my wife and I were trying to understand and deal with the mystery of Myeloma, we were frightened, confused, perplexed and only seemed to hear about the horror and downside of this bug. It was pretty scary! Well, I decided to write this article to tell ALL OF YOU AS NEW PATIENTS that there is another side, an upside, which is filled with optimism and great prospect. We can deal with this disease and the various treatments and afterwards, enjoy a pretty normal, if not, higher quality of life. Are there exceptions to this result? Yes! But any of us could also be run over by a bus on our way to work, couldn't we? My advice is for you to minimize the time you dwell on the negatives and get your mind concentrating on all the positives, such as, WE GET TO LIVE FOR MANY MORE YEARS WITH OUR FAMILY, CHILDREN AND GRANDCHILDREN. This is the Miracle of a Stem Cell Transplant - MORE LIFE! I am here to tell all of you, hang in there. You WILL get through it and WILL be just fine.

We must still understand that we are dealing with CANCER and not a common cold, so, there are discomforts and challenges, but they are manageable. You may lose your taste buds, your hair and some dignity, but you regain time and a whole bunch of fresh, virgin stem cells that are collected from your own body and then put back.

Here is my spin on how my wife and I have worked with Myeloma, (and a spinal operation), and continue to do so everyday. We had the Transplant and came out the other side just fine; I am walking, carrying golf clubs, working out in a gym, eating, drinking and living a very happy, and probably, a higher quality of life than before. There is GREAT living after Chemo, Radiation, Hickman lines, Stem Cell Transplants and all of the other stuff you might experience. Establish a GREAT, POSITIVE ATTITUDE and sincere TRUST that you CAN get through it and you will. Only you can really believe and help you. Others can support you, but whatever you think in your own mind is the most important.

I understand that Multiple Myeloma is one very nasty bug-er and if given the choice, I would have definitely passed it by – and said “No thank you very much.” I didn't have a choice and neither do you. The good news for all of us is, that it is controllable with chemo and a transplant, and we do resume enjoying our lives. There is always GOOD NEWS and OPPORTUNITY in adversity. Some day there WILL be a total CURE for Myeloma and maybe sooner rather than later. Researchers are showing excellent test results with new chemicals and treatments these days and we have every reason to be cool and optimistic. For now, we just have to have faith and enjoy the extended living time that a Transplant gives to us. No one can control the duration of their life, but we can all control its quality and what we do with it. I CHOSE TO MAKE IT THE BEST I CAN EVERY DAY! You need to do the same.

In addition to being diagnosed with Multiple Myeloma, my wife, family and I had the challenge of dealing with a spinal tumor operation. I had a tumor that was so invasive in my spinal column that it created paralysis & incredible pain. In only a few months, I went from being active to being unable to walk. After the surgery, I had no balance and only minimal strength and feeling in my lower body. This lasted for almost eight months. My movement revolved around the use of a walker, and in later months using canes or crutches. I grabbed just about anything that would allow me to get vertical and move my skinny butt around. My once muscular body was transformed into this good-looking bald guy with very skinny arms and legs. I was only about 80% of my original body weight. Okay, Okay, so I was probably a little–well, maybe a lot–on the heavy side, and maybe I needed to go on a diet but this spinal operation and Chemo diet sucked.

Imagine the shock to my system, going from playing hockey two or three times a week to not being able to walk. It was a challenge even to scratch, anywhere! My hockey career was finished in an instant due the risk of injury to my body and bones. But it wasn't a big deal after playing for over 52 years. I had my fun and now this grandpa is over it. I'm not quite ready for checkers at the local McDonalds yet, but giving up hockey was no problem. (I still miss all the laughs and kidding around with my buddies, but that's about all I miss).

The tumor and resulting blood tests identified that I had Multiple Myeloma. WHAT the hell is that? (I can state unequivocally that my paralysis and virtual loss of mobility was a greater mental challenge for me, than dealing with the Radiation and Chemotherapy treatments for Myeloma. Man! I couldn't walk, get dressed, make a sandwich, shave or

drive a car! This made me so mad that I decided to get with MY OWN MENTAL program and learn how to walk again, get through the chemo, the transplant and get my butt back to work and on the golf course. I set myself a group of strong visual goals that I repeated daily. I can now proudly say, I achieved every one of them. I still need some help to rebuild my business and get out of debt, but I HAVE FAITH & BELIEVE that I will get that other miracle!

As a side note, because of the back surgery and associated rehabilitation, I developed a very deep respect and admiration for those who must use a walker or wheelchair to get around. Their strength and sheer determination is unbelievable and they are real HEROES to me. You have no idea how many rude, ignorant people are out there when you are struggling to get through a door with a walker. If the automatic door doesn't work, good luck beating anyone through the opening. I was pushed, had walk around people in malls, shoved out of an elevator and watched as I struggled to get the walker folded and into a truck. It was quite a life lesson. On the other hand, there are also great Samaritans out there to whom I say thank you very much. To the others, you will notice the mistletoe over the back of my belt.

There were many things that I couldn't handle, and the air around me was definitely pretty BLUE on some days. It was sheer frustration more than a bad attitude. The fact that I was unable to walk or fend for myself was devastating. For as long as I could remember my life was alive and very active. I managed to keep up to the perpetual activities of two sons and I often thought to myself, this time you have some work to do - So Get Going!

My self-pity built up because of my perpetual dependency on my wife, family and friends and because I had this strange form of CANCER. (It is really okay to feel sorry for yourself some times as long as you get can get passed and move on.) You will receive great support and love from many caregivers who somehow find the extreme patience to understand and help you along. Your moods will shift gears throughout the treatments but that is normal. You will feel hungry and then not be able to eat. You will be sleepy a lot of the time but rarely in a lot of pain. Learning to BE A PATIENT WITH PATIENCE IS DEFINITELY TO YOUR ADVANTAGE. In my own case, my loved ones were unbelievable but my bride and mother-in-law were in a special class all by themselves. I could never return enough love or say THANK YOU enough and they were the best examples of living love I have ever experienced.

I watched my wife take on this huge health burden and do all the things that we once shared in our marriage. She and her mom were my Superwomen. They are a good part of the reason I was so determined NOT to let the surgery or Multiple Myeloma stop me from getting my life back and accomplishing all of my goals and ambitions. They never complained—at least not where I could hear it—and just let me concentrate on getting on my feet, taking the chemo and dealing with whatever the doctors and protocol threw at me.

Getting totally better became my obsession. I envisioned walking with my wife down the golf course and seeing my new, precious grandson playing with me and growing up. I just told myself every day that I was going to get stronger and regain my independence, and these thoughts drove me forward, every hour of every day. YOU ARE GOING TO HAVE TO BUILD SOME GOALS OF YOUR OWN TO HELP YOU AS WELL. It is not a hoax, it really works. I never personally doubted that I would walk again or get better after the transplant. If we don't believe in ourselves, who will? As humans, we are the only species who have control over our minds and our thoughts. We are the only ones who can help us. I was motivated to get by all this stuff quickly, and I DID IT!. You will also get through all the treatments and the transplant and you HAVE A GREAT FUTURE. THINK ONLY GOOD THINGS!

LIFE IS A GIFT TODAY AND EVERY DAY. MAYBE THAT IS WHY IT IS CALLED THE PRESENT! There are no reasons to miss out on anything or to give the Multiple Myeloma any more energy than it had already taken from us. POSITIVE works and I remain very determined to move onward and upward. I look forward to living my life every day. Some where I know we will also find help to re-build our business. I have a lot to give back. Believe it or not I registered GREAT ATTITUDES 10 years ago, (see [www.greatattitudes.com](http://www.greatattitudes.com)), long before I even knew the word Myeloma. We all have some special friends in our lives and I am blessed with many. I am especially grateful to my buddy Rob, who made sure we and our company survived financially so we could have another shot at achieving success. I thank and share my health victory with him, and many others.

My back surgery actually happened, midnight on January 13, 2001, at the Sunnybrook & Women's College Hospital in Toronto, Ontario, Canada. It was successful. The tumor was removed without complications or the addition of metal apparatus into my spine. Excellent! Time, great support and my determination were all I needed to regain my ability to walk, and I realized I had plenty of all of these. With a struggling business, a new grandson and a lot of other goals I wanted to accomplish in my life, I wasn't ready, (and am still not ready), to BE A CAREER PATIENT. After only two weeks of being bed ridden in the hospital, I pushed myself to get out of there. I also had the support and motivation of

two great friends to help get me on my feet. I will always remember and love my new friends, Don and his wife Paula. I effectively convinced the rehab therapists to have me released to home by my 57th birthday on January 26th, since I had my new portable basket on wheels. How could they refuse such a dedicated and charming patient? They didn't and home I went.

The doctors started to treat my Cancer and Myeloma with a series of five radiation treatments on my back almost immediately. My back was healing up pretty well so they moved right along. (I loved the little ink tattoo they put on my back as a target for the X-ray machine. I couldn't see it and still haven't, so it might be a picture of anything - rude or otherwise!)

After radiation, I was equipped with an amazing invention called the HICKMAN CATHETER. Having finished with all the chemo treatments, giving what seemed like hundreds of blood samples and graduating from my Stem Cell Transplant, I can tell you that the HICKMAN LINE is an AMAZING DEVICE. It saves your body from a lot of needles, poking, pinching and puncturing and makes it easy for you and all the nurses. Initially, it is a nuisance, to have all this white plumbing hanging from your chest, but after while, you get used to it and actually forget that it's there. The Hickman Line is your friend throughout the treatments and is a very important instrument for the transplant protocol. It is NO BIG DEAL and it is removed from your body easily after the transplant. So don't get stressed about it in your body. All you are left with is a very small blemish.

My treatments of VAD Chemotherapy began within days of the radiation. Here is where I was introduced to another amazing invention, the INFUSION POUCH. This hooks up to the Hickman Line and slowly dispenses controlled amounts of chemo chemicals into your body over a few days. It is all done through a power pack, into the Hickman line and then into your blood stream. AGAIN, NO PAIN IS INVOLVED. You wear it for three or four days and it is disconnected. YOU FEEL NOTHING AND IT IS ACTUALLY QUITE SIMPLE AND NEAT! Without the line, I am sure I would have felt like one of those old lawn soaker hoses with all of the needles that would have been required. The Hickman line gives and gives and all you have to do is keep it cleaned and serviced at the hospital every week. (You don't need a plumber just one of the great nurses). Although you do make many trips back and forth to the hospital for cleaning, it is enlightening.

Here is something I can share with you. I made the visit to the hospital upbeat and a pleasure. The nurses were always happy to see a happy face with a GREAT ATTITUDE. It was cool making them laugh and letting them know that we as patients really loved and appreciated them. I never miss a chance to thank them for their work, time and dedication. It became one of my main purposes on the weekly visits. The nursing team for Chemo at Sunnybrook and the Transplant Unit at Princess Margaret, were all amazing angels to me. They were kind, considerate, professional and great individuals to meet and get to know. As I said before, one thing you have to learn is that the PATIENT has to be PATIENT! There is a lot of waiting around for treatments, but when it is your turn you get their full attention and when you leave you feel that you received all the attention you needed and expected. LEARN PATIENCE AND KEEP DOWN THE STRESS LEVELS FOR YOU, OTHER PATIENTS, THE NURSES AND EVERYONE!

Going to the hospital was also also a reality check for me because I had to go to the Cancer Centre at Sunnybrook for my treatments and Hickman cleaning every week. I was aware—when I stopped feeling sorry for myself—that there were a lot of other people around me, too many people, also being treated for all types and forms of cancer. This weekly vision helped me to stop and think about how lucky I was that I only had Multiple Myeloma, as compared to so many of the other types of cancer that existed in the heroes that were around me. Patients were of both genders, of all ages and races. I remember thinking that none of us had ever met before, but we still all have something in common. Why not help each other with support, some laughing, and provide each other with a light friendly attitude? I became humbled and overwhelmed by the upbeat personality of these women and men. They talked softly and some joked loudly with their family, friends and nurses. Most laughed from fear. Those who were too serious about their battle were eventually forced to lighten up and laugh with us, including all the reception staff and volunteers. Stay light when you go for treatments. You are in good hands and must do as you are told, so there is no reason to be uptight or stressed out. Big breaths are in order and so is humour. One of my own therapies was joking with the receptionists and nurses about my hair, or lack of it, and my hot wheels, non-motorized walker without a stereo.

I think this is when I made a further commitment to myself and really knew that I could beat all this stuff. I also made a personal commitment to try to help other patients and families get through the Multiple Myeloma chemotherapy, hospital visits and stem cell transplant process. Just maybe I could make it a little easier for them. IT IS UNFORTUNATE WE HAVE THE DISEASE. BUT WE HAVE TO GET OVER IT AND LOOK AT THE POSITIVES. This is my personal philosophy that I felt I might share with others to help them deal with their challenges. I am really happy to give a little back to you and hopefully, many other patients and to the system that helped me. I have always been blessed with seeing a glass that IS HALF FULL and of having a GREAT ATTITUDE. I seem to be able to make people laugh and feel

good. With or without financial stability in our lives, we can always give good thoughts and encouragement to others. How rich am I? Giving back was a little mercenary since I really enjoyed helping the nurses, doctors, and the new patients by showing them that a great thoughts and a big smile really work. I cannot deny that IT IS A GREAT FEELING TO MAKE OTHERS COMFORTABLE AND A SEE THEM A LITTLE LESS FRIGHTENED. My wife and I have been there and know the thoughts, terror and fears that grip you day to day. There is light at the end of the tunnel, and YOU ARE NEVER ALONE. Life looks better and you will see it from a different vantage point.

There are a lot of stories and experiences I could share, but here is one in particular that affected me. One gentleman I met was waiting with two of his buddies. He had flown in from Jamaica to be treated for Cancer and was receiving on-going chemotherapy through the pouch every day. I had 4 treatments of VAD and he was scheduled for 20 or more. He had other cancer problems, not Myeloma. We talked about everything from politics, fishing, golfing and sex to joking about the chemo pouches and the fact we might actually glow in the dark. He wanted to turn out the lights in the waiting area of the hospital just to check it out. The time I met my friend was mid summer and we made an agreement that I would fly to Jamaica with my wife in December for his annual Christmas Party and Celebration. He cracked me up for weeks when he told me about his plans for the coming Christmas parties. He told me he was going to have TWO parties in 2001 instead of just the normal one. One was for all his family and friends who have supported him through his battle and knew he would live every day to the fullest. It was going to be a gala with lots of food, drink, music, gifts and dancing. The other party, was for all those people who refused to believe he would deal with the Cancer thing. They were going to get water, tea or coffee and a boot out of his house. I remember laughing and telling his story for many months. He was a strong man with a LIFE WISH and he gave it everything he had right to the very end. WHAT A GREAT ATTITUDE and pleasure to have crossed paths with this hero and gentleman!

There were many other stories from cancer heroes at Sunnybrook and Princess Margaret. I continue to think—Myeloma is no big deal compared to all the others. I regularly ordered Merlot or Chardonnay bags as replacements for the bags of chemo mix or pamidronate. They never did comply but that didn't discourage me from asking for it. I enjoyed making the whole process fun for all to keep the stress levels down. YOU ALL NEED TO DO THE SAME. I even called the Princess Margaret the Hotel Princess Maggie. Honestly, I told them, they could decorate the place a little. Basic white and beige with a touch of white and beige are not my choices for the Royal Suite I would be using for 2-4 weeks. It did match my skin color at the time though.

By the way, when you go in for the Transplant, take your own pillows, books, radio, CD player, laptop and whatever else will keep you connected to your home. I had pictures and all of the above around me. You have a lot of time to kill, in addition to the disease, so go prepared to keep yourself amused when you are not walking the halls.

Please don't misunderstand me, I DO NOT take the fact that I have Multiple Myeloma lightly but the reality is that I and YOU just have to deal with it. We didn't ask for it! We don't want it! We can't do anything about having it! So I say just move on! We can either be a full-time PATIENT or a GRADUATE SURVIVOR with a happy disposition and a great attitude. My choice and yours should be the latter and to live every day to the limit. NEVER LET YOURSELF JUST BE A PATIENT. You win and all your caregivers win. The doctors and nurses win and you produce positive results based on your own mental attitude. Everyone wants you to win and in my case they were a great inspiration and a lot of fun to be with. I cannot say enough about the roles of the hospital staff who looked after me. They were a pleasure to be around and many of them continue to care for me once a month, when I visit them for my "oil change" of the bone hardener, PAMIDRONATE. Ah yes, the monthly bisphosphonate drip to make the old bones harder. Big deal, we have Myeloma. Go ahead and maximize being alive and able to smile and do good every day!

Okay, you get the general gist of my personal adventure and challenges. Hopefully I am convincing you to have a GREAT ATTITUDE about your health challenges, about life, and about sharing with others and getting the most out of every day. I am truly lucky to be given more time no matter how many years are in the tank. I can walk again and I am doing everything I did before, except contact sports. I am more aware of how good it feels to play golf, and I guarantee you that I do not take any part of any day for granted like I have in the past. I am in the life Queue again and it really does feel good. I have my faith and I control my thoughts, so why not make them good, positive ones? I have come through with flying colors and so will you.

During the process, I encourage you to set personal goals. I had several. I want to be around to see my new grandson, Ryan, grow up and get married. He is now 2 (as of June 2002), and my wife and I missed him for a whole year in 2001 due the risk of coughs and colds when he was a baby. He is now walking and talking, and we love him and are really enjoying him a lot. Ryan was on our mind every day during the chemo and transplant process. He won't know for years to come how much of an inspiration he, his mom and dad were to both my wife and I. My second son was also attentive to whatever we needed, be it moving offices, driving or just talking. He was a strong support particularly during the back

operation. I have two great kids.

My third goal was to give myself the chance to make our little 9 year old business a booming success. We have struggled to get exposure and sales and actually lost a lot of ground to minimal activity last year. It was not a big priority in 2001 that is for sure. It will work out and as I tell my friends, IT'S NOT CHEMO! Besides, how can a company with a name like GREAT ATTITUDES fail - Right? Ultimately, we have to win. I do have my life and many other pleasures to enjoy and I believe the money thing will work out. I believe there is more than one miracle in our lives. (By the way, our company will be donating a percentage of all sales directly to Multiple Myeloma research from this day forward. Maybe sharing my business success can give the Myeloma Research team that one extra \$1.00 that helps find the TOTAL CURE for this stupid form of cancer.)

To make my point about GETTING ON WITH IT, the next time you are on the subway or bus, ask the person next to you how long they have to live? They will have the same answer as you and I—THEY HAVE NO IDEA. There is too much to do and too much to enjoy just being alive. You don't have TIME to feel sorry for yourself and DO NOT want to give any more energy to the Myeloma.

The last fifteen-plus months was like a blur. When I present myself as the volunteer STEM CELL GRADUATE at the new patient Orientations at the Hotel Princess Maggie, I honestly can't believe all of the things that are discussed and that I actually went through it all. As the Social Worker and Stem Cell Coordinators go through their presentations to the new patients, it is awesome to recall all the victories I achieved as a Myeloma patient. How quickly we all forget and move on with our lives. Awesome!

I am very grateful to be on this side of the health issue and so will you and your families when your treatments are over and you get back to normal living. It is truly a gift and a very delicious one at that! Life will never be the same or any better for you, I promise. You will see many things you missed.

After all is said and done, I am really a different person today because of my experiences. I am a better person to be sure. Little things are now very important and I make time for things that once passed me by because I felt that I was too busy. Life goes on with or without you and I vote – WITH! We must understand and learn that we must make time for life's pleasures of laughter, holding hands, kissing, going for walks, golfing, dining, visiting friends, for making that telephone call to someone, and for just being happy. This applies to all of us, with or without Myeloma. There is no better feeling than being well again and able to smell the flowers. I have so much to be grateful for and so much more to give. I have been given a second, open-ended chance to do anything that I choose and I try every day to do my personal best and not to let anyone down, especially myself.

Thank you medical science, doctors, nurses, my great family, my precious mother-in-law, all my close friends and most of all my fantastic bride and special wife, for helping me to understand what "having a nice day" is really all about. I use to hate that saying, now it is my daily goal. All of you as new patients will be fine, so just stick with it, believe in yourself, your family, and your goals and have confidence in the system. Most of all, keep up your own Great Attitude and an open perspective on life and gratitude for the gifts you have. You do have a lot to be grateful for – so enjoy it.

I hope we can talk or meet some time and in the meantime, please feel free to contact me if you feel the need to speak to someone. YOU WILL BE FINE AND YOU WILL GET THROUGH IT!

With much love and respect,  
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