B>TO B(MT)OR NOT TO B(MT), that was the question.

by Chris Harper – July 1, 2011 at 12:04 pm

Happy Birthday to me
Happy Birthday to me,
I celebrate this birthday
with…… Chemotherapy!

Hi, I'm Chris, 58 years old reasonably fit as I like to run and kayak, and the am the fittest of my friends and family in my generation. In April 2010 I was on post Christmas diet and was feeling how slim I was when I noticed a lump below my rib cage that didn't fit with how I remembered my human anatomy. I went to the doctor on Thursday. But not before having a search on the internet and frightening myself silly, thanks Wiki! "Mobile spleen", my doctor's registrar said "but we will send you for a scan". On Friday, the radiologist started his ultrasound and asked, "Had any blood tests recently? No, ok, we will do some as a haematologist is coming in this afternoon and your spleen is enlarged".
I was called into see the haematologist on Monday. "You have Myelofibrosis (MF) and low haemoglobin (HGB); I can see it in the blood tests". I had read about MF, acute and chronic so what does that mean? "Let's do a Bone Marrow Biopsy, and then discuss it." On Wednesday, the biopsy was done under local. A slight ping as the haematologist nailed it but not an issue. Now I was even better read on the internet, I asked for a prognosis. "Results in 10 days, then we can discuss that". But the haematologist was not available for four weeks so I had to wait! My Doctor checked when the results were due and relayed the haematologist's view, I would be okay until Christmas (8 months away) and then all bets were off.

Try relaying that to my wife Lesley, kids and extended family! Three weeks of starting to pack up to leave things tidy for when I depart the planet!?

When I saw the haematologist they talked about MF and the few patients they had with it, while I asked various questions. "Drugs can mitigate but not cure and bone marrow transplant (BMT) is unproven and highly risky". I asked about prognosis and was asked, "Do you really want to know? " Many words came to mind but I settled for yes! 2-8 years survival, median 5 and you seem better than median. "Would you like a second opinion?" Yes! I was referred to a leading UK specialist, and the one I wanted to see. My last comment to the consultant was that I thought I had less than a year, "Whatever gave you that idea?" I was too emotional to find the appropriate words and left the hospital in a part stupor.
My choice of specialist related to an email query Lesley sent in our first MF research to the MPD Voice website. We were referred to a doctor and got a brief guiding response from a UK renowned specialist the same evening. That was the person for me, Professor Claire Harrison!

At the MF consultation in July I got good background information and a simple statement of fact. "Drugs can help but not cure and work well on some but not everybody. BMT is the only potential cure but has risks. You are reaching the top age limit for a mini allogenic BMT (in UK) and your fitness makes you a good candidate. If you were my father or husband, that is what I would recommend for you." This simply was another confirmation step on a decision Lesley and I had made after our early internet research. "I will refer you to my friend at University College Hospital, the best in London."

The BMT consultancy in September was reasonably straightforward. I got the details of the process, short, medium and longer term, the survival odds and many questions answered. One in 5 does not survive the process. Risk of failure or relapse is also one in five. Three in five are successful. Then there was the risk of Graft Versus Host Disease, to various degrees, afterwards. Overall nothing new arose, and impressed by the consultant and specialist nurse coordinator, I agreed to go ahead at this meeting.
We needed to find a donor so my two sisters were checked first but didn't match. Several weeks later the coordinator phoned and told me I had a 10/10 match for January 2011. Next we had two failed attempts, one couldn't match the dates and on the second I started a cold on my first day, which stalled the process until, the end of February, where my chemo started on my 58th birthday.

I checked in to my first room on the 16th floor of UCH.I could see the flats where I was born less than a mile away! Then I was moved to a room overlooking the city of London from where I could see locations where I had spent half of my working life. This was so I could be near the nurse's station for special monitoring as the chosen drug regime (the gold standard for MF in Europe I was told), Fludarabine, Busulfan and then ATG (Thymoglobuline) is not used frequently as they have lots of BMT patients but not that many with MF.

Six days of intravenous chemo, then three of ATG conditioning. It seemed easy until day 7 at 17.15 hrs when my body was bush-wacked and I went into a twilight zone of headaches, sore throats, diarrhea, hourly loo trips, shivering and many other unpleasant reactions, with very little sleep, for the next 3 days. Things started to settle on the day I got my new stem cells and then I had two more twilight days before starting to improve. Whilst I found these days very difficult I simply remembered what the doctors had said "You are going to feel more ill than you have ever done before" . They were right! Some days I ate, others I didn't because I couldn't swallow (ice lollies (popsicles) were great for my throat). Now began cell watch as we watched them drop so that I became neutropenic and then rise. The counts for HGB, Platelets, Neutrofils and White Blood Cells, would help determine my release date, alongside my general health.

I got apologies from doctors and nurses for doing various bits and pieces at all times of the day. My response was always the same; 'you are saving my life, do whatever you have to do whenever you have to do it and I will handle it'. Even though I was often wired up intravenously, sometimes for a few days, I got up every day as much as I could and they had to find me a 15 minute shower slot every day. The nursing staff team, truly multi-national, were brilliant. Always cheerful, friendly and supportive, nothing was too much trouble. However, my best nurse was Lesley who stayed and slept on a sofa in the room, or during my twilight days sitting in a chair sleeping with her head on my bed.

I noticed that a week after receiving my donor cells, my spleen had reduced from five fingers below my ribs to one, something I was told would take weeks. I thought that things were going slowly and perhaps I had received my donor stem cells from a female who was now "late for the date". One of the doctors confirmed it was a lady donor, the only information I was allowed. Lesley hoped that this would help me like going shopping and watching Grey's Anatomy, but I explained to her that there were simply not enough lady cells in the world to achieve that.

On day 15 after transplant I was changed from a mixture of intravenous drugs and pills, to just pills, but forty a day! Two days later I was told I could go home, loaded with emergency contact numbers, but would be attending regular clinics. Standing in the hospital reception, waiting to go home, I felt the four weeks spent in hospital drift away as if they had not happened. I left with a limp as my big right toe and left knee both became very painful with 3 days to go, believed to be an inflammatory response related to the return of neutrofils adhering to old wounds. I couldn't do much at home as I felt really tired and cold all of the time, frequently shivering despite multiple clothing layers, reasonable weather and the heating on. Walking was still an issue and I exacerbated this by jarring my back by missing a step down. I really walked like Quasimodo for a week until that settled. I found that my taste buds were shot and some favourite drink/food was no longer palatable.

So began regular hospital check up visits, every Monday and Thursday, a very early start as I was given private transport by the hospital to protect me from infection. I had an additional day most weeks if I needed blood transfusions for low HGB. I had a number of continuing minor problems like shivering, tiredness, lethargy, dry mouth, that, toe excepted, were par for the course. Overall I was told that I was doing well for so soon after transplant and had been the third quickest out of hospital for my treatment regimen. During this early period I had good days and bad days, being able to walk for an hour one day and having no desire to walk anywhere on another. Being cold and shivering were a constant. Sometimes I could concentrate and do things and others not; this was probably due to chemo brain. But as time has progressed I felt better.

9 weeks post transplant and I felt almost normal.

My HGB had continued to drop slowly for a while but transfusions stopped at this time. My Chimerism - carrying two types of genetically different cells - was checked and two of the three main cells, T and N, were 100% donor with some residue of me in the B cells; the likely cause of HGB issues. The doctors could see immature cells in my blood, a clear indication that my bone marrow was getting started. I had had level 4 scarring of the bone marrow another potential factor in slow marrow development. My son took advantage of my new found energy and I was decorating, plumbing and doing other DIY activities in his flat without feeling tired.

People criticise the National Health Service in this country but I have nothing but praise for the doctors and nurses I met along the way and the treatment I received. Even the food I received was okay!
I used an MPD chat site to get information in the early days and now have many friends around the world. I wrote a small email based blog on the site to give back and share with others considering SCT/BMT. I now do the same on the MPNForum facebook page.

I lost weight, muscle tone and of course hair, not that I had much. I was completely body bald like an oven ready chicken; but it all came back. I was very careful who I mixed with and stayed away from young children and their parents/grandparents as my immune system was compromised, but I considered this a small price to pay. After three months I was using public transport again, although quite careful where I stood. After 12-18 months I was re-immunised against childhood diseases except Measles as a live virus was seen as too risky. I had been ready to go skiing one year after transplant but did not as there was a Measles epidemic in Europe and more importantly, France, but I have been many times since. I am now back kayaking and running and simply getting on with my life as normal. After three years I was having six monthly checks with the transplant team and just take two Penicillin tablets each day.

I then moved on to annual checks but stopped checks and penicillin altogether after six years. I now carry on as normal and travel a lot. I have met many SCT buddies around the world and have been to a few 'Second Chance At Life' transplantee symposiums in the USA. In 2018 I had my Measles Jab as this disease is on the rise again and I was visiting countries where it was prevalent. I can now travel anywhere except where there is yellow fever risk as the combination of transplant and age make the inoculation a risk and I don't wish to push my luck.

Myelofibrosis is rare and those of us who are suitable for transplant an even smaller number. Two years after the transplant, I was able to meet my donor Sarah and we are now friends. I also do buddy work for MPN Voice and help others who are considering SCT or going through it. I have met, and made friends with, people all over the world. I will harangue anyone about SCT, to increase awareness and to encourage people to join the bone marrow registry in their area as many still can't get a match. I will continue to do this to express my gratitude to the medical staff who helped me. It is not an easy path to tread and can be a physical and emotional roller coaster, but it is worth it as the prize is life.
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