Patient Story 3

I got the news on the 3rd of November 2017.

'You have a form of cancer called Multiple Myeloma and it can be treated.'

A *form* of cancer. Not the death-sentence Cancer. And it could be treated.

This delivery of the diagnosis made a huge difference to the way I received the news and to how I then relayed it to my family and friends.

It can be treated. Not cured. A cure was never promised, but it was stage 1, early days, caught on time, and it could be treated. And furthermore, there was a clinical trial open and I could benefit from the latest research into my disease if I wanted to.

What was a clinical trial? Was I to be a guinea pig for some strange new drug? What even was this illness? Myeloma? Melanoma? Completely different I was told! What was the treatment? What difference would a clinical trial make?

So many questions. So much new information to take in. Over the next week or so, I had several conversations with the doctors. Everything was explained in detail, the nature of my illness, the current protocol for treating it, the new drug that would be the subject of the trial, what my involvement could be.

This trial was to involve the regular treatment protocol for Multiple Myeloma and a dose of an extra drug on top each time I had treatment. The drug, called Daratumamab, has already been used to treat patients who relapsed, but this was a trial to examine its efficacy in newly diagnosed MM patients. It gave me a measure of comfort to know that the drug had been used before and that I was not a complete guinea pig!

I was given lots of paperwork, outlining the protocol for the trial, huge detail on all the drugs to be used in my treatment, from chemical names to multiple side effects, I had to sign a lots of permission papers and then was asked if I wanted to be part of the conversion trial, that is, giving permission to make the results available to convert into usable data in the lab. I consented. Many people had been in trials before and had got us to this stage, so I felt it was a good thing to be part of the trial and to contribute to medical progress so as to bring us one stage further. Without all those others who had gone through a trial process before me, there would be the data today to treat me in this way.

There were huge benefits to be being on the trial.

All dates for treatment were hit spot on, there was never any delay, I was never bumped off the list - the protocol for a research trial is stringent and delays can affect the results so some level of priority is given to trial patients. Come snow or storm (and they did), the show must go on.
I have a point of contact at all times, and can be in touch with my medical team at any time. (within reason - it is the mobile number of the clinical nurse director - not to be abused!)

I was treated as anyone not on the trial would be - with induction therapy in the form of weekly chemo for 4 months, then a break before an autologous stem cell transfer, a small break again before continuing with consolidation chemo for a further 8 weeks, and am now on maintenance therapy, receiving an infusion of the trial drug once every four weeks, a regimen which will continue for two years. See all the new vocabulary I have!

The major difference is that although the regular treatment has concluded, I am still being seen and checked once a month. I am being treated with a drug that would otherwise be unavailable to me. Balanced against the minor intrusion of the monthly treatment, the offset is that I am monitored and still have a lifeline to the medical team. I am not yet cast adrift. All my dates are already booked in advance, the organisation and efficiency of the research team is second to none and I am assured of continued care.

I am honoured and grateful to be part of this trial, affording me access to the latest information, research and expertise in this area, and humbled to know that my contribution may help to treat and possibly cure others in the future.