



A RELATIVES PERSPECTIVE OF MDS

Written by Margaret Shepherd

Daughter of Johanna Conlon
(25th October 1936 to 5th April 2015)
who passed away from MDS

When one person in the family has cancer, the whole family are affected by the diagnosis and Myelodysplastic Syndrome ("MDS") can be a particularly challenging illness to treat and live with.

My advice to families who find themselves in this situation, is to be open and honest from the start. You must accept the fact that your lives will go on hold, but sharing your fears and frustrations will bring you closer than you could have ever imagined. And it is this closeness that will guide you through the toughest of days and give you the strength to go on fighting.

My mum was an active, fiercely independent woman but with a particularly rare and severe type of MDS I had to witness her simply waste away in a matter of months. I miss my mum deeply and contrary to what people might think or say, time, nor faith will ever fill the void I feel in my heart.

SOME FACTS ABOUT MDS?

- *Myelodysplastic Syndrome ("MDS") is a malignant blood disorder due to bone marrow failure.*
- *Most causes of MDS are not known.*
- *People don't die directly from MDS, but from complications caused by the symptoms and effects of MDS.*
- *There are a small amount of cases that progress to become Acute Myeloid Leukaemia ("AML").*
- *There are many treatment options, but in some cases, without stem cell transplantation, life expectancy is greatly reduced.*

Here's my story:

Part One

My mum's symptoms of breathlessness, chronic fatigue and an on-going chest infection (that showed little signs of improvement, even with antibiotics), became a real concern in April 2014. She'd had an operation in February 2014 to remove her gall bladder and blood tests at the time had revealed a higher than normal white blood cell count.

More in-depth blood tests during the months of May, June and July showed unexplainable irregularities and abnormalities in the way her blood cells were behaving, but it wasn't until a bone marrow test in early August 2014 that she was diagnosed with Myelodysplastic Syndrome ("MDS").

Mum's case was immediately transferred from the Whittington Hospital, Archway to University College Hospital, London and the consultant told us that mum had a very rare type of MDS called "MDS/MPN-Unclassified". This meant she had similar characteristics of both myelodysplastic syndromes and myeloproliferative disorders. Myeloproliferative disorder is the name for a group of conditions that cause blood cells & platelets to grow abnormally in the bone marrow.

Sadly, due to my mum's age and current state of health, a stem cell transplant was out of the question, but non aggressive chemotherapy and regular blood transfusions could help with symptoms and give us more time.

Not knowing much about MDS I found out all I could about the disease and particularly what my mum's prognosis entailed. I found it helped us greatly during the consultations when we would ask questions. I also believe it encouraged the consultant and MacMillan nurse to be more forthcoming and honest with what was going on. As a family, we especially needed to prepare ourselves, as we had already lost my dear dad to cancer seven years previous and my two nieces had recently lost their father to cancer.

Mum's low intensity chemotherapy treatment began in September. She received the drug Azacitidine (also known as Vidaza) administered by injections, for seven days with a three week break between courses. I'd only read really good things about Vidaza, so we all felt somewhat relieved that treatment had started so quickly and mum appeared to be responding really well.



Over the next two months, mum took special care with her diet and by eating well and getting plenty of rest, her energy levels increased. She found things to do around the house, in order to keep her mind busy and began the laborious process of getting her personal and financial papers in order.

She continued to attend her weekly session at Bingo, went clothes shopping more regularly, did more gardening and took up knitting again.

She'd said to me, what was the point of feeling depressed about a situation she had no control over. It was either stay in bed and moan, or get out and live!

Although mum did attend one counselling session and had plenty support from her MacMillan nurse, she'd told me she found it easier expressing her feelings to us, her family. She said it helped clear her mind and knowing how we felt and how we were coping, kept her strong.

In November, mum needed to be hospitalised for two weeks, due to on-going chest palpitations, dizziness, chronic nausea and severe headaches. Initial thoughts were that her symptoms were simply an on-going result of the side effects of chemo, but blood tests revealed an unexplained sudden growth spurt in her platelet count. A condition known as Thrombocytosis. As her platelet count continued to soar, she was prescribed Hydroxycarbamide (also known as Hydrea) – another chemo drug in a tablet form, used in addition with the Vidaza.

I'll never understand where she found the strength to keep going, what with all those trips to and from the hospital for blood tests, blood transfusions, chemo and the endless array of appointments and consultations. When I asked her did she ever feel like just giving up, she said she wasn't ready to go yet.

One day mum was waiting to be picked up by ambulance to take her to chemo and I asked her why she had several small boxes of chocolates in her bag. She said one was for the driver, one for the staff on the front desk at the MacMillan Centre and the others were for the lovely nurses. When she left, I sat on the sofa and cried my heart out.

MDS UK note:

Sadly, Johanna's MDS did progress, and she passed away a few months later. She died very peacefully and surrounded by her family, and her daughter lovingly describes how everyone prepared for this, which she says helped a great deal. We decided to publish this story here as it may help other patients and families facing similar circumstances.

If you think these sort of details may upset you, please don't read further.

Part Two

Christmas came and went and it was probably one of the best we'd ever had as a family, but come January, my poor mum ached all over. She had tiny reddish pinpoint rashes all over her body, was short of breath and she suffered from fluctuating bouts of chronic diarrhoea and acute constipation. A blood test revealed she now had Cytopenia (a rare side effect of some chemo treatments). This condition meant there had been a significant drop in the amount of red and white cells and her platelets were also now extremely low.

By February, my lovely mum looked pale, exhausted and she was not able to continue with chemo anymore. Her body was scarred and badly bruised from needles and she was on a high dose of both pain and anti-sickness medication, the latter to counteract the effects of the pain medication. She still went for weekly blood tests and transfusions at the hospital, but there was little improvement to how she was feeling. We noticed she would take to her bed more often to sleep and her appetite was poor, so our visits became more regular, as mum became more dependent on us to do her shopping, cleaning and cooking.

My sister, nieces and I, rallied round best we could, but juggling full-time careers, taking time off for hospital appointments, time spent travelling, maintaining our own homes and caring for mum often left us physically and emotionally exhausted. Feelings of anger, frustration and guilt constantly played with our minds. Were we doing enough to help mum? Could we do more? Were we putting our jobs before family? Why were we so tired? And why weren't there more hours in the day! It was often our mum who pulled us through these dark dank periods, raising our spirits by what she said and what she did.

On Monday 2nd March, with low blood pressure, acute anaemia and a chest infection, my mum was admitted once more to UCH. Given her grave condition, she was put in her own room and was receiving outstanding nursing care.

Sadly, however within two weeks, mum developed an aggressive mouth infection, which left her unable to eat any solids. Her gums and throat were red, bleeding and blistered and she found it difficult to swallow. She was short of breath and receiving that many blood transfusions, that a pic line was inserted to help ease her discomfort. Funnily enough though, her sense of humour never waivered and I would often witness moments of banter and the warm familiarity she shared with the doctors and nurses, who tendered her. One nurse told me that my mum had the kind of laugh that inspired the feeling of joy.

A meeting was called on Friday 20th March in my mum's presence. My sister, nieces and I were there, as well as mum's consultant, MacMillan nurse and a group of nurses from the Palliative Care Team. The consultant was very honest, supportive and forthcoming, as it was explained to us that antibiotics were not working. Mum's bone marrow had stopped functioning as the MDS had progressed to a critical stage and there was nothing more they could do.

I recall how devastated my mum looked at the prospect that she would never be going home again and now hospice care was being looked into as a matter of urgency. The whole situation felt so surreal. This was it!

On Monday 30th March, all treatments and medications (with the exception of pain relief) were stopped and my mum was transferred by ambulance to the North London Hospice in Barnet. My sister and I were there that day to meet and greet her in her new room. We'd decorated it with fairy lights, flowers, cards and photographs in an effort to make it feel more homely. Mum's weight had plummeted. She was pale, frail and in a great deal of pain. I remember the look on the ambulance driver's face, who helped lift her gently onto the bed. There were no needs for words, we just exchanged glances and as he left the room, he just looked at me and I saw his eyes were full of tears.

We spent the next few days visiting mum, sitting around her bed and trying to make sense of everything that was happening around us. The raw reality of impending death and yet, strangely enough we still had moments of denial and hope!

When mum wasn't sleeping, we talked about life, religion, her funeral and what to do with her ashes. We cried together, laughed together, hugged a lot and held hands whilst watching TV. Mum appeared happier than she

had been recently, now that her pain was under control and being managed in a way that didn't leave her feeling disorientated or too sleepy.

By Friday, mum's temperament had changed. There was a serenity about her as she lay there, deep in thought. Staring at us with an occasional smile, as she drifted in and out of sleep. It was as if she knew it wouldn't be long and there was no need for communication any more. I believe she'd felt we'd said all there was to be said and now all we had to do was wait.



On Saturday 4th March, around mid-day, mum fell into a non-responsive sleep. My sister, nieces and I were there at the time. All we could do was to sit there watching her intently, seeing her breathing changing from laboured and fast to a more faint and slower pace. We made ourselves at home, best we could, drinking copious amounts of tea and coffee and telling mum how much we loved her. We chatted and laughed amongst ourselves in the hope that mum could hear us, sense our presence and be comforted at the thought she would not die alone, but surrounded by her loving family

My mum passed away in the early hours of Sunday 5th April (Easter Sunday) with her family by her side. It was a little before 5.00 am and I was holding her hand, when all of a sudden she gave out one big enormous gasp, followed by a long sigh. She was gone and in that moment of quietness, all you heard was the muffled sound of sobbing. Mum had stopped fighting, the sun was coming up and the birds were singing.

It was a cold, still morning and there was a beautiful dewy mist hovering just above the grass in the gardens of the hospice. For my sister, nieces and myself, it had been the longest night of our lives.

Thanks to the North London Hospice, my mum died with compassion, dignity and in relatively little pain. I will be forever grateful to all the doctors, nurses staff and volunteers, who showed so much professionalism and kindness and gave us so much support.

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**CHRISTMAS 2013
MUM WAS ALWAYS UP FOR A PARTY
AND THAT'S HOW WE WILL REMEMBER HER**