

OK Margaret, thank you for agreeing to do this in the first instance. I guess that you have lots of stories within your story really that you've experienced health care and social care from different aspects so I just wondered if you'd like to share with us your experiences and sort of start from the beginning really or start wherever makes sense?

Yes Sandra, thank you, I was diagnosed with Wegener's granulomatosis back in 2002 and my experiences of the health care at that time were very positive. The only blip was I do recall the GP telling me to prepare for something sinister. I was having problems with the lungs and breathing and coughing and a lot of other complications but I do remember before I was actually diagnosed the GP did say 'look, this x-ray is looking serious, prepare yourself for something sinister' and looking back that was a little bit jumping the gun I feel now. It did put the fear into me from that, really from the word go and yet when I eventually saw the consultant it was quick actually it was a fortnight appointment, it was obvious then to him that cancer wasn't at the top of his list

So could you just say what the actual condition means?

Yes it's called Wegener's granulomatosis which is named after a German doctor who came up with this idea of granulomas. So basically I have too much immunity and that works in on the body and attacks organs, so it's a multisystem illness. In my case it was limited Wegener's which means that the lungs and the nasal cavities were affected. In other patients, it could be the kidneys and that's called general Wegener's granulomatosis. But it was quite a long diagnosis period. Well I'm saying long - it was three months. But when I do look at the complications of the illness and how difficult it was to detect I think really the consultant did extremely well. I've heard since of patients who've taken a year to be diagnosed with this illness - so it was quick. He had a very good team. I was allocated a Macmillan nurse, I soon built up relationships with the phlebotomist with taking bloods, at that time it was on a weekly basis and I was seeing the pharmacist, all these health contacts, the radiographer. It was a very good team and I think that was important because I needed the confidence to wade through all the tests that were ahead of me. Some were more invasive than others and in some cases it was bloods, but it was also x-rays and biopsies and the more invasive it was, I felt I had no fear really going into these procedures but the confidence I had in the specialist did waylay a lot of my fears and worries

And it sounds like the fact that everyone was working as a team

Yes, it was collaboration and very good dialogue between primary and secondary care. The GP was always well up to speed with what was happening. And when I needed a referral into the mental health side (my mother died in the middle of my having the illness), which I'll talk about a little bit later on, so I did need a referral for treatment of depression and the Macmillan nurse was a key player. The care spanned across different hospital sites, probably 15 mile apart so I think, when that happens, the collaboration's really important. And I have to say that the specialist didn't hesitate in referring me to a clinical psychologist for some psychotherapy. And that was a turning point for me as well. Having that care of both the physical illness and the mental health side, which was depression, brought about by bereavement but also brought about by the physical illness in that I had to come to terms with suddenly being quite an ill person after always being very healthy. So that's basically what happened.

It sounds like you know what worked well for you then was the fact that people were anticipating what you needed, along with you, rather than you being sort of left? Yeah?

Yes, I think that's right. the specialist he was the one who did spot that I was very, very down and it wasn't doing me any favours with the physical illness. So it was immediate, he just said 'yes, a referral' and I got that appointment quite quickly with the clinical psychologist and she was very pivotal in my journey of recovery and building a new life, living on my own all of a sudden and getting back into the workplace. So she was very, very important as was the Macmillan nurse. There was a lot of reassurance coming from both Macmillan nurses, there were two and I got to know both of them. But they were very good from a reassurance point of view and occasions when I needed to ring up. And it was obviously harder to access the specialist although I have to say his PA was wonderful when I did need to find out perhaps the result of a blood test or the result of a biopsy. But yes, the Macmillan nurse was really a key player in the treatment. And to jump now to what happened with my mother, it was incredible really that we both fell ill at exactly the same time

So how long had you been ill before your Mam was ill?

Well it might have been one of these situations that because I was caring for my mother for quite a long time, and I do wonder looking back if that put me in jeopardy really. But I was working full time and I was looking after me mother and I could feel meself really going downhill but just assumed it was stress and feeling a bit off. And the symptoms of my illness were so gradual at first and then all of a sudden there was quite a severe attack. But I do wonder quite, you know, what the carer role that I was undertaking, what part that took in me becoming ill meself and I perhaps should have asked for more support; contacted social services and got more help. It might have well been available but there was an independent streak to me that I was trying to handle things within the family really. So my mother had arthritis and a lot of back pain and in hindsight I think that masked the real problem that she did have which was eventually diagnosed as cancer. It was Non Hodgkin's Lymphoma of the spinal cord. And I think I had put too much faith into some of the tests that me mother had and a lot of that might have been due to the way my illness had progressed and that when I did have x-rays, there was a result. When my mother had an x-ray it was clear, apart from the arthritis but, there was nothing showed up on that x-ray and I think I did place an awful lot of faith in that test. And I think my mother did as well. There was a sigh of relief 'oh there's nothing there. The x-ray's clear'. Little did we know at the time that we should have pressed for a scan because my mother's pain did get worse and worse and she started to be quite down and didn't want visitors any more. Well she'd always been very sociable, so there were signs that she was more poorly than perhaps we all knew. But of course it's seeing those signs for what they are. It's easy to look back and recognise now but, at the time, we were very much fighting fires in that I was trying to get on top of my illness. We were both having appointments, our files were getting thicker and thicker all the time and it was just getting so complicated. But our two illnesses did impact on each other I feel, looking back. It came to crisis point when one night my mother got up to go to bed, tried to get up and, just her legs had completely gone and she said 'I've got no feeling'. We rang the doctor and they said they would come out the next morning which they did and we did wonder was this a stroke or something of that nature. We just didn't, we didn't link the back pain with the loss of use of the legs really at that point. And I almost had to carry her to bed that night and in the middle of the night I had to carry her to the toilet. It was obvious something really was serious. And the next day the GP did an immediate referral so my mother was admitted straight away and we saw a number of specialists that day; there was a lot of waiting round you know in the department but it was obvious they were going to keep her in really and do more tests. There were more x-rays and there was the scan which immediately revealed a tumour and we then had the journey

of moving from one hospital to the other. I think there was more investigating operation and then a referral to a bigger hospital a few miles away as she ended up in intensive care and that the actual care of her at that point, it was wonderful really. I remember some Philippino nurses, the care was just terrific you know and she got settled at that hospital and then we were to move again to a bigger hospital because by that time it was obvious she was going to need the oncology side. So, still we were very concerned but it wasn't sort of really ringing alarm bells yet; when we got to the oncology, she started having radiotherapy and you did get the feeling that that was quite intensive, just the marks on her body when I went to visit her. I thought 'oh this seems quite an intense treatment in the radiotherapy'. No one was really explaining.