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A WINDOW INTO LIVING WITH VASCULITIS

THE REALITY OF LIVING WITH VASCULITIS AND THE ROLE OF THE NURSE IN THE MANAGEMENT OF THE CONDITION

I was relieved when I got my diagnosis of Wegener's granulomatosis, at least then I knew I did not have Crohn's disease, that all these strange symptoms were related, and that there was a valid reason why I had been feeling so rotten for the past year or so. Vasculitis is a group of rare, systemic, auto immune conditions, where the immune system attacks the blood vessels. Delays in diagnosis and treatment lead to irreversible organ damage. There are 18 known conditions. Some call them diseases, but this sounds like they are contagious, which they are not. Because Wegener was involved in the Nazi concentration camps, the name of my condition changed to granulomatosis with polyangiitis vasculitis (GPA). This new name also describes some of the symptoms of my condition.

We are told we are rare. I was told six-in-a-million, but since I have been diagnosed, and through our support group, I have met so many people with the same condition. I suspect, therefore, that this number is much higher and that the lower estimates are due to either delayed diagnosis or misdiagnosis. My life and that of my family changed very dramatically. I was a young mother who had a job I loved, and we looked forward to lots of adventures in life. Suddenly, I was not as independent anymore and was unable to return to work. Our future changed overnight, physically, socially, and financially.

There is no cure for vasculitis. We manage it with harsh medications and often have ongoing issues with drug side-effects and unmanaged symptoms. These are not life-threatening, but do impact our quality of life. For example, I developed a saddle nose, whereby the cartilage in my nose was eaten away during active disease. I now have a huge cavity into my sinus area. This was not life-threatening and my disease was under control, but I had frequent sinus infections, lots of sinus pain, and a deformed nose that drew lots of unwanted attention. I did not recognise myself in the mirror between this flattened nose and the usual steroid side-effects. I found it hard to not let this interfere with my life or that of my family, so it was a blessing when I met Prof Malata in Cambridge Hospital, who agreed to fix my nose with a piece of my rib. This changed my life. I still have lots of sinus issues, but now I look reasonably normal. Who knew I was a little vain?

I think for people living with a chronic condition, a lot goes on beneath the surface. We get up and get out, we attend to things like other people, turn up for our appointments, and life seems good. But behind closed doors, there is usually a lot of effort going into being independent. We usually plan everything in advance, we prioritise what is important to achieve that day, we manage pain levels, fatigue levels, and our psychological wellbeing. I enjoy a reasonable quality-of-life, but I am sure you would not think I practically roll out of bed every day, just to get up on my feet.

Even though I worked in the health profession for nearly 20 years, I had never heard of vasculitis, and if I had, it did not register. I now see a different side to treating people. I see the importance of listening and not claiming to know everything. I despair if someone comes to me and says they are an expert, as I fear they will not seek alternative opinions if they do not understand what is going on with me. I know my own body and how this illness affects me. If I suspect something is not right or recognise a familiar symptom, my first port-of-call is the specialist nurse at our clinic. Sometimes all it takes is to talk it through and we can solve it quickly, which is good all round. I do not want to exacerbate my condition with anxiety and worry. Awareness within the healthcare team allows members to move quickly and avoid a crisis developing. We, the patients, and the clinical teams rely so much on our valued nursing staff and are very grateful to them for their role in managing the disorder.

I found having a rare condition very lonely. It was hard to explain what was wrong with me, never mind telling people the name of it. I can see their eyes glaze over before I finish the first words. That is why I started looking for a support group. I finally met another person with GPA who lived fairly near me and the relief in being able to talk without explaining everything was so good. That was the start of Vasculitis Ireland Awareness (VIA). It is a safe place to meet and chat, share information, and learn more about how we can live better with these conditions. We welcome all who are living with any of the vasculitis conditions, their families, carers, and all interested healthcare professionals. We can all learn so much from each other and save valuable time and resources.

We have meetings online on the first Monday evening of the month and are planning our annual conference later in the year, when we meet up with healthcare professionals and service providers to share details of the latest research projects we are involved in, best practice guidance, and available services to help us manage our conditions better. If you are interested in learning more about us and our work, or would like to know more about how vasculitis might affect the quality-of-life of your patients, please do not hesitate to get in touch. You can join our mailing list or come along to any of our meetings. ●