

COMMUNITY FOCUS

Keeping a positive outlook: Margaret Monk

Steve Chaplin

For a long time it was believed that haemophilia caused bleeding only in boys and men. It was known that women could be carriers and their risk of significant bleeding problems had been documented, but medical attention focused on the more apparent bleeds in the male line. Specialists knew there were other inherited disorders that caused excessive bleeding but they were not easy to diagnose and, in the wider world, awareness was generally low. A woman with a severe bleeding disorder was a complete enigma.

Margaret Monk was born in 1941; she was diagnosed with type 3 von Willebrand disease (VWD) when she was 20. This form of VWD is the most severe – levels of von Willebrand factor are undetectable – and the rarest.

"People don't know what it is. When you say what you've got, they look at you blank. They don't know."

Margaret had many visits to hospital to treat bleeds but a diagnosis proved elusive for years:

"All I remember was my mother having to take me round to various hospitals to try to find out what was wrong. But they all kept saying the same thing; that women didn't have haemophilia."

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Despite having lived with a rare and severe form of von Willebrand disease for nearly eight decades, Margaret Monk (pictured, centre, with her husband and daughter) continues to enjoy an active life – and believes that being active helps her stay positive

As a young child, she was not overly protected. In the '40s and '50s, girls did not have access to the variety of sports on offer today, but Margaret couldn't make the most of even the limited opportunities available at the time. She did PE and played netball at junior school; when she went to technical school she commuted on her bike, but she didn't join in with school games. There were days when ankle bleeds were so bad that she was unable to go to school; when her bleeding disorder was recognised, she was fitted with orthopaedic shoes to stop her ankle from turning over. Her father taught her to swim.

"I used to go swimming with the school, but other than that... I always remember the worst thing is the pain – and it still is. If you've got a bleed in a joint, the pain, nothing stops the pain other than the treatment."

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In those early years, bleeds were treated with rest, compression and patience. It was not unusual for Margaret to spend weeks in hospital waiting for the bleeding to stop. She recalls being in a cot with her arms strapped down as she received one of many transfusions, and taking an iron supplement to compensate for blood loss. Cryoprecipitate changed all that, though by modern standards treatment was still a lengthy process.

"It was long, drawn out performance, because the cryo came in bags and it had to be defrosted in bowls of hot water, and then each bag was put up like a transfusion. And it depended on how bad the bleed was how many bags you had to have – so, you were there a long while."

One of Margaret's most frequent problems was bleeding from the gums and she had many visits to the dentist. Eventually, he referred her to the local dental hospital and they put her in touch with Dr Katharine Dormandy, who established the haemophilia centre at London's Royal Free Hospital. She was a specialist in VWD and at last made the diagnosis.

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By now, Margaret was married and she and her husband Frank were uncertain whether to start a family. Dr Dormandy encouraged them to try and they had a daughter. She was tested within two days and

found to have VWD, though in a milder form. Margaret now has three grown-up grandchildren, one of whom has a very mild type of VWD that has little impact on his life. After her daughter was born, Margaret remembers being upset that she also had VWD, but she finds consolation in the fact that it is much more manageable than her own condition.

"She was always a bit of a tomboy and she did have falls. The thing was, you got to know that, all right, she did bleed a little bit more than other people do, but not like me. She was a Girl Guide and she used to go to camp with them; they used to go away for a week. And obviously, I had to tell them that she'd got this. The lady that ran the Guides is still a friend now, and she was well aware because of me; she was well aware of things and they knew that if she had a fall or something..."

Medical advice at the time was that more children would be too great a risk for Margaret. She was experiencing very heavy periods, and although these had been controlled by a combined oral contraceptive, the Tube journey to and from work in London's West End was still challenging. Margaret had learned needlework at school and enjoyed her job with an embroidery company, sewing gold thread on military uniforms. Sickness forced her to give up commuting during pregnancy and the company set her up to work at home.

Margaret has nothing but high praise for her haemophilia care over the years, but her other encounters with hospital care have not always gone smoothly. It took some time to persuade the team that she wanted a hysterectomy: she had been told not to have any more children, so it seemed the best solution to heavy periods. Finally, they agreed; she was 40.

It was probably during this admission, when she was treated with cryoprecipitate daily, that Margaret was infected with hepatitis.

"Touch wood, I've cleared it with these tablets, and for a lot of the other haemophiliacs it's all been cleared, which is helpful. Because you had problems with that, with the hep C, with the liver, and you were having to have liver biopsies which meant you were in hospital for two days... You forget about it all, but it's all things that fill your life."

She now has on-demand treatment with Voncento (factor VIII/von Willebrand factor). She has not been able to inject herself and so must visit the hospital, which is a taxi ride away.

Venous access had become limited by the time Margaret was in her sixties. She had injured her elbow at age 14 and, suspecting a break, it had been immobilised. This led to loss of mobility in the joint and muscle wasting, which has remained with her. She could not use her right arm for infusions, so the left arm got twice as much use and the veins suffered. Surgery to create an arteriovenous fistula was suggested. Neither Margaret nor her husband were keen, but in 2015, shortly after her husband died, she agreed.

She has always relied on her good arm but heavy use can provoke a joint bleed.

"I've always done everything with the left arm, and because I've got quite a big garden and now I'm on my own, I think I moved some of the flower pots and it started to... And eventually I



Margaret (pictured with her husband, Frank) has not always found her experiences with hospitals to be straightforward. However, she has nothing but praise for the care she has received from her haemophilia centre, and believes that staying in close contact with them is important in ensuring that issues can be dealt with effectively when they arise

thought, 'This is stupid. I'm going to have to go.' And it was bleeding, so I then had to go every day for four or five days."

She also recalls how a bout of food poisoning ended with a fortnight's stay in hospital. Margaret was feeling sick and fetched a bowl.

"I went to sit in the chair and the next thing I knew I'd passed out and hit my head on that windowsill. When I came to, there was blood everywhere, out of my nose. Of course, my daughter keeps on at me to keep my mobile phone in my pocket, so I phoned her. She doesn't work too far away and she came, called the ambulance... So, I ended up in hospital for two weeks, and I'd fractured under the eye and there was a minor bleed into the brain. I had all these tests, in there for two weeks, treatment every day for six weeks!"

Margaret's enjoyment in swimming came to an end when she had her knees done. It's not widely known that a replacement knee weighs about the same as a bag of sugar; two of those and you don't float very well. She and her husband travelled a lot until the insurance got too expensive: Frank had heart problems and Margaret's VWD attracted a penalty of several hundred pounds.

However, Margaret makes sure that she continues to have an active life. She has lived in the same house for 42 years and is a busy member of the community. She walks as much as she can (though the state of the pavements is a constant worry), goes on coach trips with her friends, and goes to the theatre with the local bowls club. She is an active member of her local church, which is just across the road from her house, and makes the teas for the weekly meetings there. Her family are also nearby:

"They come round and help me with things in the garden and things indoors, or when the lightbulbs have gone because I can't stand on the chair or steps anymore."

Margaret has lived with the most severe form of VWD for nearly eight decades and she knows a thing or two about being positive.

"I find with the garden, if you can go outside for an hour – I mean, obviously you've got to be careful – or when I go for a walk or even just go on the bus shopping and come back, it does make you feel better. And because I've got continuous pain in my knees all the time, it's arthritis... but mentally it makes you feel better, I think. It's no good sitting indoors trying to ignore it; you're better to go out, have a walk, come back and you feel better."

And that, she believes, is good advice for anyone with a bleeding disorder and their parents. Let your children have as normal a life as possible and keep in touch with your haemophilia centre – because without their help there are going to be problems.

"And nowadays, there are so many things, children can do anything. There are all these different sports and gymnastics and all that – we never had all that when we were children. And perhaps if the children do these various things, perhaps it makes their joints more strong so that they perhaps don't have so many bleeds."

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