

Patient profile

Munich, 12 April 2005

I was born in 1943, and have been married for more than 30 years. We have two grown-up children: a daughter and a son. My wife and I live to the south of Munich, between Munich and Lake Starnberg.

First of all I studied business economics. After graduating I didn't feel quite satisfied, so I decided to study and become a teacher of economics. It was then that I discovered my love of teaching. I moved through a number of posts until, by the end of my career, I was the principal of what was then the largest business school in Munich.

I did lots of sport. At first I played mainly handball, and made it to the state team. While I was a student I worked as a skiing instructor, and taught myself to play tennis; I always enjoyed that, and liked being able to compete with younger people even when I was getting old. So that was basically my life: career, family, sport... that was how I spent my time.

In 1998 I suddenly developed back pain. I thought: oh well, I must have been sitting too much, or doing too much sport, so I'll go to the orthopaedist, and I'll get myself a new office chair to make sure I'm sitting properly. The orthopaedist did an x-ray and said to take something or other and to get fango and massage. That was all very pleasant, but it didn't make any difference to the pain. After a while, the pain wasn't getting any less, and the orthopaedist didn't know what was going on, so he decided to send me for NMR tomography. And that was pretty much where it all started. I went for NMR tomography – my first time in the tube – and after about two hours we had the result. They told me: you've got a tumour on your spine, which has restricted your spinal canal to the size of a small crescent, and there is a suspicion of plasmacytoma. That was on 28 October 1998. I should also mention that that was my last day of work, because by the next day I was in the operating theatre, and the whole process started. One or two weeks, perhaps two weeks, after the operation, the first biopsy was taken, which they sent to pathology so as to verify the result.

I was shocked. First of all I couldn't believe it. For me, cancer for me was something... my first thought was that I was going to die. Before I knew anything about it, the doctor in charge handed me a manual about multiple myeloma, which was really meant for doctors. The first things I saw were: an incurable disease, medium life expectancy – as they so nicely put it – three years, or around 36 months, but the figures didn't mean anything to me at that stage. I just thought: right, now you need to get ready for the end, and make sure your exit's as smooth as possible. Get everything sorted out here, so that you don't leave behind any chaos, and then just say right, so that's that then. To be absolutely honest, at that time I got myself a grave, because I thought to myself: you can't just leave your wife behind. If you've got to go, then you should at least spare her that worry, because there's quite enough for her to take care of as it is.

Of course, the family was also deeply affected, and for them that also came as a big shock. On the other hand, it also suddenly brought us very close together. It was suddenly possible to talk more openly than before, because before that conversations had been more superficial, because that's how life is, but now we opened up more and let these conversations happen. And friends were also... well, it's hard to know exactly how to treat someone who's got cancer. As for me, at first I didn't want to have anything to do with the outside world – it was like I had fallen into a big pit. But then thank God I started getting active again, and things started to sort themselves out.

I was lucky enough to be able to go to a big centre, Grosshadern Clinic, where they specialise in relatively obscure diseases. After the operation, I started getting radiotherapy as well. And then Grosshadern Clinic and a second clinic, the City Centre Clinic, explained that they were working on a special study about plasmacytoma patients. That was in 1999. It was a new process which can give you quite a long period without treatment, in other words a period of remission. It was a high-dose autologous therapy, which means that they give you back your own stem cells.

Then I had a remission of two and a half years, in other words a period where I didn't have any treatment, apart from the long-term bisphosphonate therapy. Bisphosphonates are for building up bone tissue, because this disease very strongly stimulates the cells that break down bones.

But, all in all, I must say that things were great for me in 2000 and 2001. I went skiing again, and played tennis, although not quite as hard as I used to. I didn't play any more handball, but I did some refereeing to keep myself involved in the sport. As I had always been pretty active, and now wasn't working any more, I was now on the lookout for some kind of new activity to keep me busy, and then I found it in the form of the self-help group.

That really was an eye-opening experience. When I went along to my first group meeting, everyone took turns to introduce themselves a bit, and one of them says: I've had the disease for 20 years, or perhaps 18 years; and I thought to myself, I can't believe it – so I don't have to die yet after all! People can live with this disease for a long time.

My work with the self-help group makes a difference to my life on a daily basis. Once a week we have our regular day at the office. We have regular group meetings in Munich every two months, and now we have also set up a separate group for family members who have different needs. Our group meetings are mostly for sharing information, or finding out about new kinds of therapies, and occasionally a doctor might come and give us a talk.

In 2003, or late 2002, I suddenly had a relapse. I had to have radiotherapy on other parts of my spine. Then they tried with Thalidomide, and Endoxan – that's cyclophosphamide – but that stopped working after a while, and then they gave me Velcade, just after it had been approved in the USA. That gave me a remission of a year and a half. So again, for a while, I didn't need any treatment. I realised I wasn't quite back to my old form, but still... and then just now, at the beginning of 2005, unfortunately I've just had another relapse. So now I am in another phase of treatment, where they are trying to combine Velcade with dexamethasone, to see if that will have an impact.

My personal experience of the illness has been fairly short and intense. Life goes on, despite the illness. Maybe the possibilities are limited, but other possibilities open up. You need to keep your eyes open for niches where there is something you can do. You've got to be open, go to a self-help group, exchange your experiences with other patients. We can learn from each other. Self-help doesn't mean doing something for yourself in private, but rather coming out of your shell and supporting each other, helping each other - and thereby helping yourself, too.