

Liz Clark - Personal Statement

My experience with cardiac issues started in January 2003 when I decided to leave my job with The Learning and Skills Council due to a fright with my health. My health problem involved seeing a Cardiologist several times and, on the last occasion, I mentioned that I had decided to retire. After suggesting that this was not really necessary, the Cardiologist said that, if I really intended to retire, I might like to consider becoming a patient representative on the Peninsula Cardiac Managed Clinical Network (PCMCN) which would involve approximately one day a week. After consideration I agreed to join the Network.

My knowledge of cardiac issues was extremely limited so I spent the first few weeks visiting different people who might help me broaden my knowledge. Part of my self education process involved contacting various voluntary Heart Support Groups and talking to the members. My experience led me to decide that, in order to represent patients in a meaningful way, I had to establish a structure which would allow me to gather the views of a wider group of people. With the Network's agreement I organised a patient/public event which was open to anyone in Devon and Cornwall with cardiac experience. Approximately 100 people attended and 26 of them volunteered to be part of a patient group. Some of the volunteers only wanted to attend meetings if they were near where they lived but others were happy to travel further. I therefore selected 10 individuals from those who were prepared to travel to meetings and the group comprises two people from each Healthcare area. I arranged our first meeting to be in late 2003.

The group have continued to meet every 4-5 weeks; one or two of the original members left or died but they have been replaced with others and we now have a group of 16 regular attendees. I ensured that, from the outset, we had a visiting speaker at the meetings to help broaden our knowledge of cardiac and related health issues. I consult the members about their views on specific issues and relay them to the Network Management Group. I now represent patients at other cardiac meetings across the two counties of Devon and Cornwall.

I am also a representative on the Department of Health's CHD Primary Care & Heart Failure Sub-Programme Board and a Trustee of the Heart Care Partnership.

My knowledge regarding Drug Eluting Stents is based: on discussion at the Network Management Group which started in December 2002. NICE guidance on the use of DES was not due to be published until late 2003 so the Network drafted interim guidance which was eventually circulated to all Chief Executives. The topic has been discussed many times since 2002. The most recent action has been to raise awareness of the *BCTS statement on stent thrombosis and Drug Eluting Stents* which describes concerns relating to stent thrombosis.

In addition to this I observed a patient in the Cath Lab at the end of pci treatment., also, some members of the Patient Group have stents fitted and they occasionally refer to their experiences.