

Louise's story

I had a cardiac arrhythmia diagnosed in 1986 shortly after my daughter was born and had my first ICD implanted in July 1988. My symptoms were black-outs and fits which happened suddenly and for no apparent reason. Initially it was thought that I had epilepsy, but luckily for me it was quickly discovered that I had a cardiac problem and not a neurological one. I say 'luckily' because I know people who have been treated for epilepsy for years before it was discovered that in fact they had a cardiac problem.

I was treated with various types of anti-arrhythmic drugs but it became clear that they were not going to be able to prevent occasional episodes of VT and VF so I was given an ICD. I now know that my condition is a re-polarisation disorder, which results in VT and VF. It is still unstable and although I am on carefully regulated medication, I rely on my ICD to get me through each episode. I later learned that I was only the twelfth person in the UK to have an ICD.

Despite these on-going problems and the fact that I will never be allowed to drive again, I try to live my life as 'normally' as possible. I have a daughter, now aged 25, I worked full time for a publisher up until 2002 and now work for them as a freelance. I am also a BACP Accredited Counsellor working in private practice. I take holidays abroad including trips to the USA and Japan as well as to many European destinations. I also travel alone when I need to. I do not feel that I am 'ill' and unless I tell people about my condition, no-one would ever know there was anything wrong with me.

However this 'normality' takes effort and energy especially as the emotional demands are great. I constantly live with the fear that I might black-out at almost any moment and this is difficult to cope with at times. Even after so many years, I sometimes feel that it might be easier and safer to just stay at home. Making the effort to go out to work, travelling on the tube or the bus, sometimes feels like I might be taking a big risk. I belong to an ICD Patient Support Group which means I can give support to others and take support for myself when I feel vulnerable myself as even after all this time, this still happens occasionally.