

Convener of The Public Petitions Committee  
Scottish Parliament  
Edinburgh  
EH99 1SP

28th October 2012  
Revised 7th February 2013

Dear David Stewart, MSP

Re: PE01446: Scottish Standards for the Care of Adult Congenital Heart Patients

I thought it might be informative to share with the committee my experience of living with a heart condition from birth.

At eleven days old, a world first for a late 70s baby, pioneers fitted me with a cardiac pacemaker. Complications were common, early pacemakers were bulky and unreliable with fragile leads, and were set at a fixed rate limiting me physically. By seven I'd already been fitted with five pacemakers, involving complex, experimental surgery. At the age of 12 a hole in my heart was repaired by open heart surgery. Around this time, I also got my first variable rate pacing system. Since, I've had a further five pacemakers, totaling ten. Two have been fitted in the last couple of years, one involving a risky procedure to remove enough old leads, all of which were left due to the risks involved removing them, to make space for the required new ones.

Mine has been a life lived in and out of hospital. A life of uncertainty totally dependent on a specialist team and a medical device to live. A life of recovering from surgery yet never being "fixed". A life of getting on with it, making the most of the good times never in doubt of just how fragile life is. Despite this, between the challenges, I live a full and enjoyable life.

I am from the first generation of adult congenital heart disease (ACHD) survivors. We all have different stories, experiences and conditions. But generally we accept our lot in life. We learn pretty early on that we must pay a cost to live. We accept this because there is no other choice and because it makes the experience easier for everyone involved. We understand that as first generation ACHD survivors the care we receive is pioneering. As such, we are willing to work with our cardiac teams and service providers to find the right answers in the hope of improving quality of life for the next generation.

However, it is deeply frustrating and disappointing when we face unnecessary challenges. It is easier to accept the unavoidable than the unnecessary hurts. Since reaching adulthood I have faced many unnecessary challenges including: Having no specialist service to move to when I reached adulthood around 16 years ago therefore, for over a decade, having no follow up of my general heart health; significant problems during pregnancy and a lack of specialist care during my son's birth; a general lack of understanding and at times skepticism from my GPs and a variety of allied health professionals often when I need have needed care most; difficulties at my local A&E including being discharged "with a virus" by a non-specialist Cardiologist despite my pacemaker, on which I am totally dependent, being faulty (and me knowing and stating this and a heart monitor clearly depicting this); no specialist A&E cover or on-call electrophysiology; difficulties being informed about and referred to the newly commissioned specialist service; being forced to choose between expertise in Electrocardiology and Congenital Cardiology; confusion about Prophylactic antibiotic cover during dental procedures; no holistic support, no psychological input (as an adult or child), physiotherapy and generally poor after care; poor understanding of "medically unexplained symptoms" and the long term impact of early and frequent cardiac intervention and being dependent on a pacemaker on the heart and the rest of the body; as a child, I had no extra support for missed schooling and constantly had to "catch up" by myself, even after being absent for significant periods of time during senior years at high school, due recovering from heart

surgery; a general lack of awareness and understanding about congenital heart disease at school, University, and other aspects of my life.

Such misguided care can't be an efficient use of resources potentially "doing harm" to patients for which the NHS then has to pay. This is more expensive when sick pay and loss of earnings are considered and many of us are parents of dependent children. It also concerns me that of the estimated 15,600 ACHD survivors less than half are known to specialist services. Where are these "lost" patients? In my opinion, it is likely that lives have probably already been lost as a consequence of inadequate or misguided care.

The NHS saved my life as a baby. For that I am deeply grateful. However, it is not easy living with a heart condition from birth. We need the Scottish Government to continue to support us, as adults, on this journey.

Adult Congenital Heart Disease is the success story of modern medicine. Scotland can be proud of its contribution to this success. The most common serious birth defect, affecting 8 per 1000, live births is now for the most part manageable. In Scotland, 450-600 babies are born each year with this condition and over 90% will now survive. It is now recognised internationally that complex congenital heart conditions cannot be "cured" and we need lifelong monitoring and care. To make the most efficient use of limited resources and to ensure quality specialist care we need National Healthcare Standards and an adequately funded National Specialist Centre. We have needed this for many years. We need to be treated respectfully with understanding about what it means to live with a serious lifelong medical condition. We need to be heard. I urge the Scottish Government to listen and to take appropriate action as a matter of urgency.

In Hope & with Kind Regards,

Dr Liza Morton