

PE1446/K

David Stewart MSP
Convener of the Public Petitions Committee
Scottish Parliament
Edinburgh
EH99 1SP

12 November 2012

Dear Mr Stewart

Support for PE1446: Scottish Standards for the Care of Adult Congenital Heart Patients

I would like to express my support for the above petition, which is due to be considered by the Public Petitions Committee on Tuesday 27 November.

Unfortunately, I missed the petition closing date, and would like to share my opinion about the importance of National Standards and an adequately funded specialist service.

As an adult congenital heart patient who attends the Scottish Adult Congenital Cardiac Service (SACCS) at the Golden Jubilee Hospital in Clydebank, I know first-hand how important national standards would be.

Last year I was admitted to A&E at the Victoria Infirmary with hemoptysis (coughing up blood), which is part of my heart and lung condition called Eisenmenger's Syndrome. With no real understanding of my condition, the emergency doctors turned to me – the terrified patient - for advice on the best course of action. Finally, after five hours of waiting, they sent me home, advising me to contact my cardiologist myself.

Frankly I was relieved to get out of there as it was more frightening that the doctors didn't know what they were doing than it was being ill. Sadly, I know from experience that I have to be fully conversant with the details of my condition and fight my corner about my care. But I have to ask what would have happened if I had been unable to answer questions and take charge of my own care – would the hospital staff have known what to do, who to contact and how best to look after me?

Consequently, I was forced to manage the (potentially life-threatening) situation myself over the weekend and wait until Monday morning to contact my cardiologist as the SACCS is not able to provide care over the weekend. I was immediately admitted for a raft of tests, treatment and observation, which continued over the next month.

It culminated in another terrifying experience at Gartnavel hospital in Glasgow. I was prepped to have a cardiac catheter to stop the bleeding blood vessels in the lung and was actually wheeled into theatre when the surgeon

came in and announced that he wasn't sure I should be having the procedure with my condition as it wasn't safe and he'd never done it before. He asked the six other professionals in the room for the history of my case and to my sheer horror they looked back at him blank-faced. I have never felt so scared, vulnerable and at the mercy of the uninformed as I did lying on that hospital trolley right then.

Although it was not my fault, I vowed never to let myself get into that situation again. It's a sad truth that I now interrogate every doctor to ensure they know what they're doing and have experience of my condition. National standards will go a long way to reassure me on this.

Congenital heart patients need national standards and specific referral pathways and protocols for healthcare professionals to follow to ensure we're given the care and attention that our complex conditions require. It should be a requirement that a SACCS team member is immediately contacted as soon as we're admitted to hospital – for whatever reason.

Our heart (and lung) conditions affect every aspect of our care because of their complexity and doctors cannot rely on the patients for information. The last thing we need to be worrying about when we're ill is if the healthcare professional fully understands what they're dealing with. We need reassurance that we're in the right, competent hands.

I consider myself lucky that I was immediately referred to SACCS when I was diagnosed with my congenital heart condition six years ago. But I know that others are not so fortunate as many doctors are not aware of the specialist service's existence. This is a worrying issue that can be addressed with the development of National Standards.

In line with the above, the SACCS needs adequate funding to be able to provide a 24-hour service and be recognised and promoted as a specialist centre through which all communication passes. Our heart conditions don't stop at the weekends and neither should our healthcare.

I ask that you consider this letter as part of the petition lodged by Dr Liza Morton.

Yours sincerely,

Jenny Kumar