



### **Sarah's story – A mother's experience**

I am a parent of a patient with congenital heart disease. I hesitate to say I am his carer now as he is able to look after himself and is an independent working man. However, when things go wrong we stick together. My son was sent straight to A&E after a GP appointment where the GP said she was worried about his temperature and other symptoms. We drove to the hospital straight away, drove round and round the car park and eventually found a place. We were processed through a shockingly busy A&E in 11 hours. Despite explaining that my son was a "professional patient", known to the cardiology department upstairs, he went through the various stages of A&E, sitting in the crowded waiting room, lying on a trolley in a crowded hall way, lying on an A&E bed answering his name and date of birth numerous times and his medical history as each clinician was coming to him new, as they took more and more blood and asked him how he felt again and again. He eventually got a bed in a ward at 1am and they "processed" him by 2am. He then spent 2 ½ weeks in hospital being treated for endocarditis-which is ongoing.

There is so much one can say about this experience... there are so many things that hardly represent ideal care, and the frustrations and the adverse features eat away at the gratitude we have for his eventual treatment. Care pathways, especially for seriously ill patients, should be better than this.