

Self-Management

I have encountered transition as an individual living with a genetic condition requiring multidisciplinary care throughout my childhood and I have been negotiating the path to adult services during the couple of years. Transition for me means going to a new hospital, engaging with many new professionals to create a healthcare team. It has felt like the predictability and my safety net has been removed and the new one is still to be created. I also feel a strong expectation to manage independently or 'self manage' when receiving healthcare. Some of the skills that are expected include taking my own medication, filling prescriptions, attending medical appointments alone and being able to ask and respond to the questions asked by the healthcare team members.

The reality is, however that if the individual does not follow through and take up responsibility for attending their appointments, getting tests and investigations done at the new health setting then they are likely 'to fall out of the system' and are at risk of poor health outcomes. To me it is like going from school to university as my care is a lot more self-directed.

One example of a chronic genetic condition is Turner's Syndrome, where adult multidisciplinary care clinics are in the process of being established at other tertiary centres. The longer term experience with large numbers of such women encountered due to the different structure of the health system has allowed the collection of more knowledge at this centre, about patterns of outcome.

One strategy to assist young adults emerging from the paediatric hospitals is to provide a checklist focusing on what tests and surveillances are required and how often. Having a checklist keeps me in control, gives me a degree of predictability and choice about when and where I go to get my tests done. It is a tangible tool that I can refer back to and keep track of what is expected of me.

There are often multiple simultaneous challenges that can be a barrier to successful transition. My biggest barrier to transition has been managing my fear of needles while becoming familiar with new places and people. I often had a number of appointments to see specialists and allied health staff from early childhood right through my years of schooling. Over time regular clinic staff would get to know me and my struggles. I vividly remember one of my last visits to the Royal Children's Hospital when I was admitted to the Day Medical Unit for a Glucose Tolerance Test and my turn to go into the 'treatment room' came and yet again I struggled when the nurse put the tube in the back of my hand. It was at this point that I was told that something could be done about it (fear of needles). I was in disbelief but said "great let's do it!" one family member said up until that point I was not ready to take ownership of my issues. In my experience however there was very little opportunity and dialogue until this point. Subsequently I learnt visual imagery techniques through a psychologist so that I could escape off to another place while having procedures. Being willing and able to take ownership seem to be significant factors in having independent healthcare.

Another initial barrier was that the process of transition seemed to be thrust upon me

without warning, and at a period of time when I was unwell. The vulnerable position I was in compounded the uncertainty of continuity of care. I felt that discussion about transition was not in the foreground till it was upon me.

With the benefit of maturity and hindsight, there may have been some indirect introducing me to my adult carers but I did not link this information at the time. Adult specialists may have been pointed out to me at conferences but I was not clear on the relevance for me.

I often felt unprepared for the differences between the paediatric and adult systems despite reading online and the information that was given to me. For example in terms of my fear of needles the adult system did not support the 'patient friendly' strategies of minimising the number of times that a person has to be punctured in the process of receiving investigations or treatment. In addition the use of topical anaesthetic cream beforehand is not the norm in the adult system. There was a need to self advocate for the cream, something I heavily relied on, to be used. Not only could I no longer use these helpful strategies but limited alternative strategies or assistance was offered. This personal example highlights the variation from a child-centred approach.

I am in a unique position where my mother is a doctor as well. On reflection, previous to my 'transition' I relied on her as a body guard and would not let her out of sight on the few occasions I was admitted for surgery. I feel that while this has often been in my favour in finding the best professionals, it has also been an extra challenge for both of us: her allowing me to flounder on my own, and me being brave enough to assert myself amid the uncertainty. It feels like sometimes I can lead the way and other times I feel as if about to fall over.

As my fears and barriers slowly break down, I am closer to self management and completing the transition process. I would feel that I have been 'transferred' not 'transitioned' as I am still working on the process of acquiring the skills of self management, and I feel that my previous service providers have terminated their responsibility for my care. This can feel like one step forward and three steps back while trying to assert my independence and frustration simultaneously.

The process of my transition is nearing completion and has proved to present a diverse roller-coaster of challenges to battle through and triumph over. To me the transition process has been not a symbol or statement of childhood or adulthood, but a process of developing my own tapestry of life skills and knowledge including a greater awareness of needs and limitations. I am both grateful and frustrated at the opportunity to have such a 'rite of passage' to the truly adult world.

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