

My name is Amy Frounks and I'm 17 years old, I am a member of NHS England's youth forum and am a young person representative in NHS England's CYP rehabilitation working group, I am about to embark on transitioning into multiple different adult services and wanted to talk to you about as a young person, what my hopes, worries and expectations are.

I wanted to start by describing my view of what transition is - transition is a lot more than the movement of a service user from a children's service to an adults service due to reaching a certain age – it is actually a monumental shift in how the individual's health is managed. We are talking about new staff with different perspectives who are yet to understand the individual's needs and a transformation in terms of a reduction in responsibility the health care professional takes for managing the health conditions to an increase in the young person's management, similar to a jump from secondary school to university in the level that the teachers check on your learning. In fact transitioning to adulthood is hard enough without the added pressure of changing multiple services and for people with long term health conditions, losing the support network of the staff they have grown up knowing – it is almost bad timing considering the quantity of other changes in reaching adulthood.

I access many ongoing rehabilitation services via the NHS that require me to need this transition process as will need ongoing rehabilitation regarding both mental and physical health.

Everyone has their own idea of a successful transition and I am no different, there has been many a time when I have thought about it and created my perspective of a model transition and it would be something along the lines of:

- Being able to have a smooth journey at an age that is suitable for me, when I am not only at a suitable age, but a suitable level psychologically so the process of having new people involved and having to create a relationship and learn to trust them doesn't phase me. Then also at a suitable stage in my life where it doesn't interfere with exams or other major transitions in life, for example university but instead complements them and the geographical location I intend to be in. This would mean have a flexible age to transition so it doesn't have to be purely at 18, it could be anywhere from 15 to 24.
- I would like to have a big period of preparation and lots of time to discuss and plan how it is going to look for each individual service and then for me as a service user of multiple services and be guaranteed that I at least start with the same level of support in adult services as I finish with in children's.

One of my biggest worries is losing the transparent communication between me and my paediatrician, I am very fortunate to be able to email my consultant as frequently as I wish and request an immediate appointment if needed but also just ask for some virtual advice.

She has seen me develop intellectually, psychologically and physically, playing a part in me growing up – she didn't have to see me when I didn't want to or had no interest in talking to her but persevered until I let her in. Seeing an adult specialist isn't going to be the same, I am going to have to learn to engage on a different level and not be able to get the same level of emotional support.

Another worry is that I have spent a lot of time on children's wards and have created relationships with all the nurses and they all know the simple things about me, what position I need to be when lying down, what my care plan is and essentially who I am and what my personality is. When I have been on the ward, I tend to be the oldest which I don't mind – a very similar feeling to being in year 6, so relative to that idea, I am transitioning into year 7 now and am going to be the youngest. Adult wards are different, they have strict visiting hours in my hospital and I could be next to someone of any age. No one on the ward will have a direct understanding of me or my conditions and I won't have an understanding of them, I sincerely worry that in this transition especially, if I end up on an adults ward, I am going to feel extremely isolated and lost and that I will slip into being another patient on the ward not an individual person. To make this be an easier transition, I would make it essential for me to see the ward I would be sent to and speak to a sister on the ward so I can alleviate some of my worries prior to a possible admission on the ward.

Whilst GP's are great at providing care for people and should be a doctor you go to when there is a worry about an aspect of your health and they are excellent at signposting you to the correct service after your consultation, they are not specialists and therefore don't have an in depth knowledge of complex conditions so as I have had such great communication with my consultant, I failed to see the need to visit my GP, instead just added any little problem on to a standard clinic consultation with my paediatrician. In adult's, I fear I am may need to see my GP more, I need to somehow learn how to establish a relationship with her and I need to do it quickly as I need her to be aware of how I operate as a person and as I struggle with trusting people, I need to learn to trust her in order to make the service beneficial – I just wish that I had realised this sooner so I could have spent longer to do this and utilised the primary care service earlier on.

### Expectations

One area I have a major concern over is the process of me leaving CAMHS, this is something I am dreading. At current I am too bad for a discharge from CAMHS yet have just been told that I am not bad enough to transition into AMHS. I have heard of this 'falling in the gap' or 'getting lost in the system' quite frequently but never thought it would happen to me. Despite having ongoing support for many years now, I am going to be discharged when I reach 18 and not transition into adults, instead I need to self-refer myself into an alternative talking therapy which has a long waiting list, so it looks like that gap is going to consume me too – transitioning is definitely not straight forward for a young person when there are different criteria's for the next service.

Of course I am expecting care across all my adult services to be different but despite having such an expectation, know that it is going to have a big impact on my life.

I have 2 and a half months till I am 18, and my first big meeting about transition is tomorrow so in that timescale am sure it will be a bit bumpier than the hoped smooth transition and I am someone who has been communicating the importance of getting it right to all my health care professionals. So those individuals who haven't thought about the changes could have even less preparation time than me and it needs to be a clear responsibility for a key health professional to inform the young person about it.

By no means have I come up here and found lots of faults in transitional processes within health care as I know that there are some excellent examples of good practice across England but wanted to bring it to a personal level of reality and explain from a young person's perspective what a stressful and challenging situation this process is going to be for me and provide you with some of my individual worries that I am sure other young people would share too.