

Good afternoon everyone, my name is Thines Ganeshamoorthy, I am 20, and I have Osteogenesis Imperfecta Type 4. This condition literally means the improper formation of bones; therefore it means my bones break very easily and with very little force. Hence, my condition is often referred to as Brittle Bones Disease. I was diagnosed with my condition when I was 2 years old. I am now fully out of transition services, my transition started when I was 16 and ended last year. My transition process left me feeling lost and not knowing where to turn.

Throughout my life, my care has been managed at various hospitals across London. This has helped me to see examples of good transition and those, which are not as good. One of the things I valued the most pre – transition was the existence of a Multi-Agency Planning Pathway team headed up by a key worker. These meetings allowed there to be a forum where all the healthcare professional around me to get together to discuss issues and to come up with solutions or to delegate to those who may be more appropriate for coming up with a solution. A key worker would organise the team and act at the point of contact between the healthcare professionals and me. This allowed me to get on with my life and ensure my disability did not hinder my life too much, however, having gone through transition this service no longer exists, and in order to get the help and assistance I need I have to personally go and chase up the individuals and seek out the help I need. This combined with the time of transition, me just starting university, has made things very complicated. It has left me feeling overwhelmed, trying to manage the impacts of my condition, as well as trying to lead a typical life with university and a social life. Furthermore, I have felt that there has been a lack of signposting to services. Everything is different in the way it is structured in adult services and if the onus is more one me now to get what I need, I do not feel I have access to enough resources to get access to things I may be entitled to.

Another thing I saw a difference between was the handover process between paediatric and adult consultants to overlook my case. At one hospital the transition process was smooth, I was told beforehand who was going to be taking over my care and there was transition appointments where I had my paediatric consultant and my adult consultant together and I had a chance to discuss any queries and questions I had while they were both present. However, this was not true at my local hospital. I was promised a combined transition appointment and a visit to the adult wards with my consultant in order to make me more comfortable with the new environment. Alas, neither of these things happened. This has made me rather apprehensive as to what to expect when I need to use these services. SO, this has lead me to question ‘Why can’t there be consistency between transition processes within the UK?’.

With my experiences, the solutions I would proffer is having a multi - agency planning pathway team up until 24 is possible, collaborative appointments with adult and paediatric services and tours of adult wards and services.

With that, I would like to hand back to you all, a chance to discuss 😊 On your tables you will find a list of questions we would like you to talk about and at the end of 35 minutes we will bring the discussion back to the wider group and we will be asking for feedback on the following questions:

- 1) Who should be responsible for transition and is there a need for a new health care professional specialising in transition?
- 2) Should there be "adolescent" wards in hospitals?
- 3) How could the transition of people with long term conditions be improved?