

Looking after teenagers & young adults with SCD



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Background

Poor transition to adult care is associated with poor adherence, discontinuity of care and poor engagement with services

Adolescence is a critical time for setting the foundation for future health outcomes

Comprehensive transitional care model provides a framework for addressing adolescent issues



What is transition

The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated healthcare systems (DoH, 2003)

A guided, educational, therapeutic process, rather than an administrative event, allowing for the far broader developmental changes of adolescence than just clinical needs

Patient's chronological age not automatic trigger for transition



Challenges for adolescents and young adults

- **High levels of anxiety about transition**
- **Low levels of readiness for transition**
- **Concerns about increased levels of self management and independence**

- **Psychological and Social Concerns**
 - - **fear of dying young**
 - - **body image**
 - - **limitations in daily activities**

- **They valued age appropriate health facility / service provision**



Concerns by Parents and Families

- - Loss of relationship with Paeds care giver
- - Concern about adolescent's ability to self manage
- - Loss of educational opportunities due to chronic illness



What we do...

Ensure Transition services includes:

- Opportunity to meet adult team
- Information about SCD
- Help with self management and education

- Practical issues:
 - - how to access pain relief
 - - Importance of clinic follow up
 - - Collecting prescriptions
 - - Medication compliance

Some of our activities:
Transition passport, Education, Support group, Peer education awareness days, Individualised planned transfer, Dedicated adolescent clinic, Extended hours, Day care pain service, TYA Unit



The collage consists of four photographs. The top-left photo shows a male and female healthcare professional sitting in chairs, looking at a document together. The top-right photo shows a group of people sitting in a waiting area with large windows. The bottom-left photo shows a long hallway with people standing in a line. The bottom-right photo shows a group of people in a meeting or discussion, with one person holding a large sheet of paper.

Guy's and St Thomas' **NHS**
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University Support events



The top photograph shows a large group of people, including students and staff, posing for a group photo in a room. The bottom photograph shows a smaller group of people, mostly young women, posing for a group photo.



What did you find useful about the Transition service

- "It was good to meet other patients in similar circumstances and to share our experiences"
- "Explained the differences and similarities in service"
- "Prepared you for how the new clinic you would attend would be structured".
- "Able to talk more about my condition"
- "Know more about sickle"
- "Just to prepare you"
- "More information was supplied in regards to the transition to adult clinic".
- "The staff were very helpful".

Survey, 2016



What did you find useful about the Transition service

- "It allowed me to understand how to manage my health better independently".
- "It helped me prepare and gave me useful information"
- "I was able to find out how new things would work when I attend the adult clinic"
- "Informative"
- "Reliable resource of information"
- "I got to understand and learn different things about sickle cell"

Survey, 2016



What would you change about the Transition Service?

- "Move over at an older age (over 18); longer transitioning period"
- "Not sure"
- "Nothing"
- "The adult service/area hospital to just be as nice as the kids and not dirty"
- "Maybe talk about it after my GCSE's because it makes me worry when I have a lot on my mind already"

Survey, 2016



What would you change about the Transition Service?

- "This is my first appointment"
- "To actually see where you will be going" and "the difference in procedures and etc".
- "I wish the adult ward was more similar to paediatrics wards"
- "The nurses come with you from paediatrics."
- " Stop treat you like a child"
- "They create a ward for ages 16-30"
- "Giving young people more time to get acquainted with the idea"

Survey, 2016



Learning life skills:

- **Self efficacy: extent to which individuals have control over events which affect their lives**
- **Associated with fewer physical and psychological symptoms and good self management**
- **Jointly identify barriers and collaboratively solicit solutions**
 - - **Planning**
 - - **Problem solving**
 - - **Decision making**
- **Assertive Vs confrontational**



Summary

- **Ensure support is developmentally appropriate and takes into account the young person's individual circumstances (NICE guidelines – 2016)**
- **Long-term condition not a hindrance to achieve individual aspirations!**



Thank you !



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