

## Clinical Guidance

### ***Young adults Health Transition Guideline for patients with Sickle cell disease***

#### Summary

*This young adult's health transition guideline provides information on best practice for staff when caring for young adults during their transition from children's to adult services.*

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# Young Adults Health Transition Guideline

***“Ensuring a seamless transfer is one of the greatest challenges facing both children’s and adult services”***

RCN 2004

## 1. Background

1.1 Access to health care tends to be at the beginning and end of life and, comparatively speaking, young adults tend to be a minority group in terms of requiring acute hospital services. It is not surprising therefore that, although there is a wealth of literature describing the specific needs of the young people and there are some examples of very good practice within the Trust, children’s services have tended to focus on the younger child and adult services on the older patient, with little emphasis on the needs of the young people. As far back as 1976, the Court Report recognized young people as a group with distinct needs and said that failure to develop a good relationship between professional and adolescent may set patterns resulting in long term poor use of services.

1.2 This document refers to the care of young people within the age group of 13 to19 and this is essentially a developmental stage, although it is acknowledged that young people under the age of 13 can have “adolescence” characteristics and will continue to develop adult characteristics well into their twenties. It is also well recognized that serious illness or trauma can cause regression in children and young people.

1.3 Transitional care is an essential component of high quality care for young people and good transition can improve health- related quality of life. A poor transition out of children’s services can have serious outcomes for young people and incurring additional health service costs. A proportion of young people with physical conditions will also have mental health problems. These should be considered when planning transition. This transitional care guideline has been developed with input from members of the multi-disciplinary team and by listening to what young people have to say. This guideline outlines best practice for general transitional care; however specialties will have specific components to their practice.

1.4 Standard 4 of the Children’s National Service Framework - NSF (DOH 2004) ‘Growing up into Adulthood’. States that young people with ongoing health needs should have a plan developed with them for the transition of their care to adult services, co-ordinated by a named health professional.

### ● **The NSF vision :**

- Young people supported to make the transition to adulthood and to achieve their maximum potential in terms of education, health, development and well-being.
- Young people taking responsibility for their own health and making informed choices and decisions regarding their emotional and social development, and health and well-being both now and in the future.
- Services and staff who are able to respond in a sensitive way which encourages engagement and provides high quality support for young people.

## **2. Transition Planning**

2.1 Transition is a process. The goal of a transition programme is to provide uninterrupted, coordinated care which is developmentally appropriate and psychosocially sound for the young person. The timing of commencement of the transition process must take into account their cognitive and physical development, emotional maturity and state of health.

2.2 The transitional care programme starts many years before the planned transfer to adult services and initially focuses on helping the young person develop independence and autonomy. Successful transition should focus on the young person but should support parents in their changing role as their child takes more responsibility for self care. The programme should be supported by the most relevant health professional /transition key worker.

2.3 The transition programme should guide the young person to become progressively independent and responsible for their health needs, enabling them to cope positively with their condition, recognising that their needs will change over time.

2.4 Young people and their families often find transition from children's to adult services stressful and confusing and each specialty will need to establish transition models that meet the needs of the young person, their parents and the service. Services for young people with mental health problem have different thresholds to care than adult mental health problems. These young people may need to access follow up care from their GPs.

## **3. Example of young adults Transition Programme**

The transition programme should be gradual and include elements of education and preparation as detailed below:-

### **3.1 Provide developmentally appropriate information at regular intervals**

Ensure information is provided in an appropriate form to meet the needs of the patient particularly those with learning disability

Include young person in their care by copying them in on letters

Include information on disease management, self care, medication, lifestyle choices (smoking /alcohol and substance misuse/sexual health/mental health problems)

### **3.2 Social Services**

Establish links with Social Services to assist with information regarding housing and financial needs

### **3.3 Promote autonomy**

Encourage the young people to initially see the clinical nurse specialist and medical staff independently. Develop independence by providing information directly to the young person not via their parents (See Trust consent policy for further information)

### **3.4 Provide Support for young person**

Provide the young person with contact details for key members of their health team (CNS, doctor, Play Specialist, Pharmacist, and Dietician, Psychologist, CAMHS clinician). Ensure the young person is aware they are free to contact their preferred member of staff directly and between appointments. Provide information on safeguarding and spiritual care in an easy to understand format.

### **3.5 Parental Support**

Parents should not be excluded from the transition process and should be invited in toward the end of consultations/ discussions. Host annual parent information evenings

### **3.6 Choices**

Provide choices regarding the timing of transition to adult services

Offer pre transfer visit, accompanied first appointment, and accompanied sequential visits.

### **3.7 Specialty Specific components**

Each specialty should review current practice and devise a pathway to suit the needs of the young adults in their specialty. This will then be tailored to meet the needs of the individual. Many young people will have complex needs and their care should be coordinated by the most appropriate key worker to ensure that they are treated in a holistic manner. The use of patient passports is encouraged (see appendix 3)

## **4. Audit and Monitoring**

The guideline will be audited locally and on an annual basis by the young people Transition Steering Group. A report will be presented to the Children's and Young Peoples National Service Framework Committee.

# HEALTH TRANSITION PLAN

## YOUNG ADULTS PASSPORT DOCUMENT FOR SICKLE CELL DISEASE

<b>Surname:</b>	<b>M / F</b>
<b>Forename:</b>	
<b>DOB:</b>	
<b>Hospital Number</b>	
<b>NHS Number</b>	

**Date 1<sup>st</sup> assessment.....**

**2<sup>nd</sup> assessment.....**

**3<sup>rd</sup> assessment.....**

**Contact details:**

Mob.....Landline.....

Email.....

## **Guidance for Health Professionals**

**This document is a patient self assessment questionnaire and will form the basis for a needs assessment to identify areas of support. This document is designed to assist the health care professional working with the young persons between the age of 12 – 17 in preparing and assessing their readiness for transfer to adult hospital. The questionnaire will help assess their competences in the following key areas:**

- 1. Knowledge of condition and treatment concordance**
- 2. Self efficacy**
- 3. Personal responsibility and self advocacy**
- 4. Emotional readiness for transition**

**This is a continuous assessment and will be used at various stages of the transition period, the final stage being 16yrs at which the expectation will be that the young person would have demonstrated a level of competence and emotional readiness deemed satisfactory to function in an adult facility.**

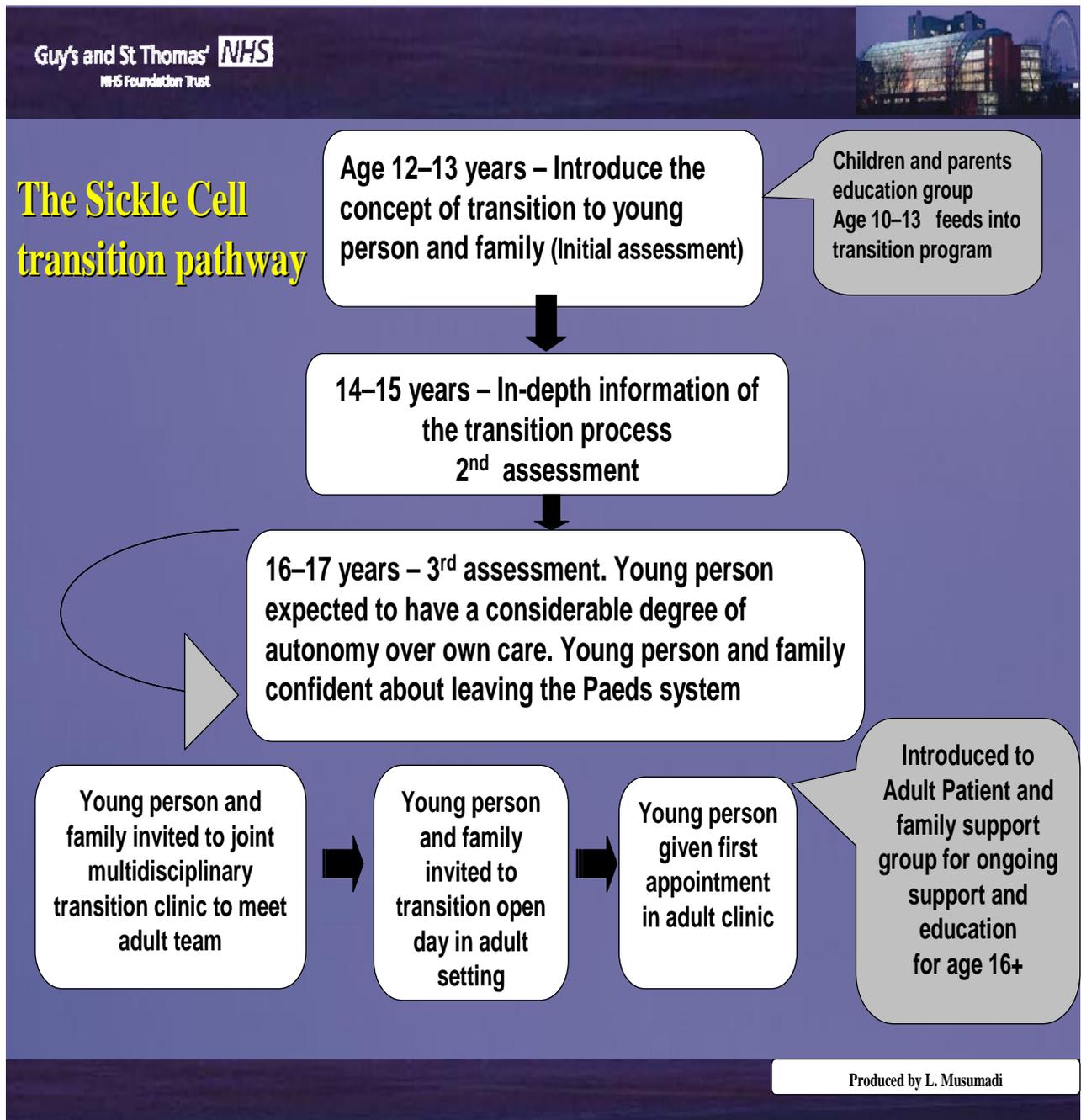
### **Assessment stages:**

- 12 - 13 years - Introduce to the young person and their family the concept of transition to adult health care.**
- 14 - 15 years - Aim to give the young person and their family a more in depth understanding of the transition process.**
- 16-17 years - Young person should have a considerable degree of autonomy over their own care. Both young person and their family should be feeling confident about leaving the Paediatric system.**

**The health care Professional will explore various items further with the young person in order to assess the adequacy of their responses.**

**NOTE: This is a legal document and must be stored in the patient medical records in line with Trust policy on record keeping.**

# Sickle Cell Transition pathway



## YOUNG PERSON'S SELF ASSESSMENT

All families are different in how much young people are involved in taking care of their health. This changes as they get older. So we want to make sure that by the time you are ready to move on to the adult hospital, you and your family feel confident to do this. To start with, we would like to find out what you are doing already and what areas you might need help with in the future. This is all about how you manage your Sickle cell disease (SCD)

Please complete or affix label	
Surname:	M / F
Forename:	
DOB	
Hosp. No.	
NHS No.	

	Stage 1			Stage 2			Stage 3		
	Yes	No	I need some help	Yes	No	I need some help	Yes	No	I need some help
<b>Knowledge about my condition</b>									
I know my haemoglobin type /Sickle type									
I can describe a sickle cell crisis									
I know the triggers for a crisis									
I know the things I need to do to prevent a crisis									
I know how to make my pain better by doing other things than just taking medicines									
I know my usual level of Haemoglobin									
<b>Consultations/Hospital visits</b>									
I understand what the Doctors and Nurses say to me									
I can ask the doctor/nurse/therapists questions									
My parents usually remind me about my appointments									
I know when, where and with whom I have my next appointments									
I keep a record of my out patient appointment e.g diary/calendar/phone									
I know the names and doses of my medicines and when to take them									

Please complete or affix label

Surname: M / F

Forename: DOB

Hosp. No. NHS No.

	Stage 1			Stage 2			Stage 3		
	Yes	No	I need some help	Yes	No	I need some help	Yes	No	I need some help
<b>Personal responsibilities</b>									
I am responsible for taking my own medication									
I keep an eye on whether I am running out of my medicines without being reminded.									
I can arrange for a repeat prescription of my medication									
I collect my own medicines from the chemist/Pharmacy									
My parents always sort out my prescriptions									
<b>My general health</b>									
I know what to do if I suddenly become unwell									
I know how to contact my GP									
I know where to get advice about different health issues.									
I do worry about my health									
I know how stress affects my SCD									
I know how sports can affect my SCD									
I know why it is important to eat a healthy diet									
I know about the possible complication of SCD									
I want to know more about how SCD affects me									

Please complete or affix label

Surname:

M / F

Forename:

DOB

Hosp. No.

NHS No.

	Stage 1			Stage 2			Stage 3		
	Yes	No	I need some help	Yes	No	I need some help	Yes	No	I need some help
<b>Growing up</b>									
I understand that my body may not mature as quickly as others									
I do worry about my size									
I know I can pass on a sickle gene to my children									
I know how to prevent pregnancy									
I know that pregnancy can affect my SCD.									
<b>For girls</b>									
I know that SCD can affect my periods									
<b>For boys</b>									
I do understand what priapism is.									
I know how and where to get help when I am experiencing a priapism									
<b>Family/Social</b>									
I have been teased or bullied about my SCD									
We talk about SCD issues with my family									
I worry that having SCD will make it harder for me to live away from my parents									
I know about the risks of smoking									
I know about the risks of misusing legal and illegal drugs									
I know the effects of alcohol on SCD									
I know how to access websites for young people including the connexions website <a href="http://www.connexions-direct.com/">http://www.connexions-direct.com/</a> and 'Teenage health freak' at <a href="http://www.teenagehealthfreak.org.uk">www.teenagehealthfreak.org.uk</a>									

Please complete or affix label

Surname:

M / F

Forename:

DOB

Hosp. No.

NHS No.

	Stage 1			Stage 2			Stage 3		
	Yes	No	I need some help	Yes	No	I need some help	Yes	No	I need some help
<b>Education</b>									
My teachers understand how SCD affects me and my schooling									
I can manage all my school work / assignments without any help									
SCD gets in the way of my doing sports and P.E.									
I feel confident that I can communicate my health needs to a college or school lecturers/teachers									
<b>Work</b>									
I have a career plan									
I am confident about discussing my SCD with an employer.									
I know that SCD may affect my ability to do certain jobs									
<b>Leisure</b>									
My friends understand about my SCD and are helpful									
I know that my SCD does not affect all activities that I might want to try									
I know what support is available in my local community and which organisations can help									

<b>Please complete or affix label</b>		
<b>Surname:</b>	<b>M / F</b>	
<b>Forename:</b>	<b>DOB</b>	
<b>Hosp. No.</b>	<b>NHS No.</b>	

	Stage 1			Stage 2			Stage 3		
	Yes	No	I need some help	Yes	No	I need some help	Yes	No	I need some help
<b>Health Transition</b>									
I understand the meaning of transition to adult services									
I understand what confidentiality means									
I feel I am ready to be seen alone for part of my hospital visits									
I find it easy to talk to my Doctors and Nurses alone									
I feel I need some support to explain my needs during clinic visits									
I feel I am ready to start preparing for transition by developing a Health Plan									
I know the names and roles of the doctors, nurses, therapists that I will be seeing in adult services and how to contact them									
I have agreed a transfer plan with dates with the members of the children's and adult healthcare team									
I feel confident that I can deal with Doctors and Nurses in A/E without my parents help									

**Name of Health Professional .....**  
**Position.....**

**Signature..... Date .....**

# Health Plan Summary

**Name:**

**Address:**

**Date of Birth**

**Main health transition needs, discussed with young person (and their family):**

**1.....**

**Action.....**  
.....  
.....

**2.....**

**Action.....**  
.....  
.....

**3.....**

**Action.....**  
.....  
.....

(continue as required)

**Can Health Plan be shared with other professionals/agencies? If only in part please specify.**

**Yes  No  Signed .....**(young person or parents/carers

## Health Professionals involved:

	Referral made to children's health services	Referral made to adult health services
Health/Clinical Psychologist	<input type="checkbox"/>	<input type="checkbox"/>
General Practitioner	<input type="checkbox"/>	<input type="checkbox"/>
Doctor (s) for specialties	<input type="checkbox"/>	<input type="checkbox"/>
Nurse	<input type="checkbox"/>	<input type="checkbox"/>
Occupational Therapist	<input type="checkbox"/>	<input type="checkbox"/>
Paediatrician	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>
Speech and Language Therapist	<input type="checkbox"/>	<input type="checkbox"/>
Child and Adolescent Mental Health Team	<input type="checkbox"/>	<input type="checkbox"/>
Learning Disability Team	<input type="checkbox"/>	<input type="checkbox"/>

### Referral made to Children's (education/ social) services/ adult (social) Services

Connexions Personal Adviser	<input type="checkbox"/>	<input type="checkbox"/>
Social Worker	<input type="checkbox"/>	<input type="checkbox"/>

<b>Copy of Health Plan to:</b> Young person	<input type="checkbox"/>
Parents/carers	<input type="checkbox"/>
Involved health professionals	<input type="checkbox"/>
GP	<input type="checkbox"/>
Connexions Personal Adviser	<input type="checkbox"/>
Transition team coordinator	<input type="checkbox"/>
PCT commissioners	<input type="checkbox"/>

Adapted from the DOH Generic template from the document "Transition; Moving on well" (2008)

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