

# **Transition to the Adult Services Network Board – December 2017**

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2017

# Moving to the adult services





- Normal adolescence
- The purpose of transition
- Transition
- **How do they feel about it?**
- How do it
- What happens if we don't do it?
- How to make it happen
- Network plan

# The Standards

- Section A: The network approach
- Section B: Staffing and skills
- Section C: Facilities
- Section D: Interdependencies
- Section E: Training and education
- Section F: Organisation, governance and audit
- Section G: Research
- Section H: Communication with patients
- Section I: **Transition**
- Section J: Pregnancy and contraception
- Section K: Foetal diagnosis
- Section L: Palliative care and bereavement



Classification: Official  
Level 1 – Specialist ACHD Surgical Centres. Section I - Transition

Standard	Adult	Implementation timescale
I1(L1)	<p>Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs.</p> <p>'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.</p>	Within 1 year
I2(L1)	<p>All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.</p>	Immediate
I3(L1)	<p>There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs.</p>	Immediate
I4(L1)	<p>All patients requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse, in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient's care plan indicates that they do not require long-term follow-up.</p>	Immediate
I5(L1)	<p>Patients, partners, families and carers must be fully involved and supported in discussions around the clinical issues in accordance with the patient's wishes. The views, opinions and feelings of the patient must be fully heard and considered, and the patient must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.</p>	Immediate
I6(L1)	<p>All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.</p>	Immediate

Classification: Official  
 Level 1 – Specialist ACHD Surgical Centres. Section I - Transition

Standard	Adult	Implementation timescale
I7(L1)	<p>Young people undergoing transition must be supported by age-appropriate information and lifestyle advice.</p> <p>Management of young people arriving in the adult service will aim to ensure that they are fully confident in managing their own condition and health care. In the clinic, they will see an ACHD Specialist Nurse who will explain and discuss a range of issues including the impact of their condition, contraception and pregnancy, and lifestyle, in language the young person can understand. The Cardiologist will discuss the treatment plan with the young person and discuss it with their family/carers when appropriate. The young person will have some independent time to talk with their Specialist ACHD Cardiologist and ACHD Specialist Nurse.</p>	Immediate
I8(L1)	<p>The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.</p>	Immediate
I9(L1)	<p>Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to partners/family or carers.</p>	Immediate

Standard	Paediatric	Implementation timescale
I1(L1)	<p>Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during <b>transition</b> and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs.</p> <p>‘Lost to follow-up’ rates must be recorded and discussed at the network multidisciplinary team meeting.</p>	Within 1 year
I2(L1)	<p>Children and young people should be made aware and responsible for their condition from an appropriate developmental age, taking into account special needs.</p>	Immediate
I3(L1)	<p>All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.</p>	Immediate
I4(L1)	<p>There will not be a fixed age of transition from children’s to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs.</p>	Immediate
I5(L1)	<p>All young people requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient’s care plan indicates that they do not need long-term follow-up.</p>	Immediate
I6(L1)	<p>Young people, parents and carers must be fully involved and supported in discussions around the clinical issues. The views, opinions and feelings of the young person and family/carers must be fully heard and considered. The young person must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.</p>	Immediate

Classification: Official  
 Level 1 – Specialist Children’s Surgical Centres. Section I - Transition

Standard	Paediatric	Implementation timescale
I7(L1)	The Children’s Cardiac Transition Nurse will work as a core member of the children’s Cardiac Team, liaising with young people, their parents/carers, the Children’s Cardiac Nurse Specialist, ACHD Specialist Nurse and wider multidisciplinary team to facilitate the effective and timely transition from the children’s to adult services.	Immediate
I8(L1)	All young people will have a named key worker to act as the main point of contact during transition and to provide support to the young person and their family. Peer to peer support should also be offered.	Immediate
I9(L1)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	Immediate
I10(L1)	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice.  Their attention must be drawn to sources of information and support groups.	Immediate
I11(L1)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.	Immediate
I12(L1)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to parents/family or carers.	Immediate



# Outpatients



# Normal adolescence

- Time of physical and emotional development changes young people into adults, capable of self-care and independent decision
- Early (11-14yrs), middle (15-18years) and late (19-21)
- **Early** adolescence is identified by physical change and sexual maturation
- **Middle** adolescence there is a rapid growth of cognitive skills and understanding of abstract concepts. Peer groups play an increasing part in identity and separateness from parents
- **Late** adolescence a sense of self, sexual identity and an increased need for closeness, affection and intimacy forms
- Family life also undergoes a series of changes at this time
- *These normal individual and family developmental processes are greatly influenced by the context of chronic illness*

*Tong and Kools 2004*

*Foster and Graham 2001*

# The purpose of transition

- Prepare young people for their transfer to adult services
- Meet the adult team
- To enable to manage their own health care, stay fit and well and out of hospital.
- Understand condition, medication and treatment plan.

# Transition vs. Transfer

- Transition is an **active process** that considers medical, psychosocial and educational needs of adolescents as they move from child centred to adult centred healthcare. (13yrs)
- Transfer is an **event** which happens on one occasion when information or people move from one place to another.

*Robertson L 2006*

*Shaw K L 2004*

*Blum RW 1993*

age 12

- letter sent to parents

age 12

- 12 yr old information pack given and discussed in BCH clinic

age 15

- 15 yr old information pack given and discussed in clinic.

age 16-18

- transfer pack sent from paediatric cardiology secretary to adult cardiologists in BHI with referral letter

age 16-18

- ACHD nurse specialist sends information. Adult cardiologist sends introduction letter.

age 16-18

- young person attends young person clinic in BHI

age 18-24

- young person's transfer to adult services completed

# Perceptions of young people moving to adult services MSc

- 'Not a lot of preparation'
- 'Scary and exciting'
- 'Adjusting to adulthood'
- 'What I might like'

# 'Not a lot of preparation'

"Yeah, when I left the children's Hospital I remember it being just a glancing comment like oh, okay, just [...] not very good so I didn't know that much about it, **I didn't know really where I was going to go.**"

(P4)

"No, nothing, they just said that it would be the same, that I'd be seen, um, **like the next one appointment] would be at the big hospital.**"

(P3)

"Um, I know I had a switch operation [...] off the top of my head, **I'm not really that sure of the details**".

(P4)

"Well the doctor like said about contraception and like tattoos, piercings and things [...] **um, that I can't really get them**".

(P2)

[The doctor said] "I think **you are old enough now to go to the adult thing** and we got some letters and things sent through."

(P6)

**‘Big hospital’**





# 'Scared and excited'

"Mixture really, exciting, and scary because I've always been at the Children's hospital **so it's like new, it's more exciting than anything though for me** [...] it's like new and its moving on but excited because it's like different and It's more aimed at you than at my parents [...] **because I'm still here [alive] and everything**".

(P1)

"Um, it hasn't really bothered me to be honest cus I felt in the last few years that I should be in the adult rather than the paediatric cus, does it goes up to 18? Yeah well, I felt like you go there [to the children's hospital] and it's like tiny children **and you think okay, maybe it's time to move on now, I'm 18**". (P6)

# 'So you can do it yourself'

*"Because it's like, **I know it sounds really weird it's like new and like more independent, so you can do it yourself instead of taking your mum with you (laughter)** it's just like don't need your parents there all the time just to say "can she do this?" when they were sat right next to me [...] "so it's just like maybe it's a chance for me to know the stuff, like I understand what I've got rather than just having to hear it from a professional and my mum". (P1)*

*"Like **don't need your parents there all the time**". (P1)*

*"Probably at first it would be a bit weird because I would probably be the only young person there [...] I think definitely after a while it would be okay **because first impressions would be quite daunting** like it is with most things, I think I would be okay with it cus in that situation you would have to cope so there's not much you can do is there?"*

# 'What I might like'

*"Um, I think probably just to give out more information about what it would be like, if there would be any changes, [...] I've not got a clue what it's going to be like but I think it would benefit people to know what exactly it would be like [...] more about where you are going, who you are going to see and what it would be like but obviously all that was said to me was "you're going to the big hospital". (P3)*

*"Yeah, we've both been spoken to but I think they are just so used to using their lingo they forget that children don't understand it [...] just like on the first visit maybe not make it so jargon". (P1)*

*"You could probably write a letter or something, maybe if it's like after an appointment or something just say on the letter afterwards you will have the choice to get shown around". (P1)*

# Issues to address in transition

- Understanding of heart condition
- Lifelong follow-up and changes which may occur
- Medication/compliance
- Diet, alcohol, smoking, recreational drugs
- Pregnancy, contraception, inheritance
- Endocarditis prophylaxis, (tattoos, piercings)
- Exercise, employment and insurance
- Jargon free

# Understanding

**Poor understanding**

91x17yrs

Condition

Follow-up

Competitive sport

Deterioration

Risk endocarditis

Smoking and alcohol

Inheritance

Contraception and pregnancy



# Having the conversation

Tell me what you understand about your heart condition?

Give the information

Ask how they receive information best

Ask them to repeat the information back

Put website links in letter



# Understanding of heart condition

- **Poor understanding of their condition**
- Reasons for lifelong follow-up
- What to do if things change
- Treatment plan
- Information, websites, support



# Medication

What do you understand about your tablets?

Do you know what it is for?

How often do you take it? 50% time?

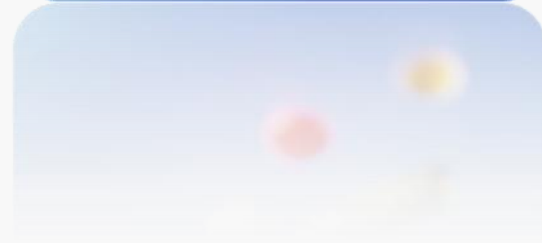
Do you know what will happen if you don't take it?

Do you know of any side effects?



# Compliance

- Medication
- Side effects
- Warfarin
- INR testing
- App Wellnote



# Diet

- Healthy low fat
- CVS risk factors
- Junk food
- Cholesterol
- Healthy BMI

**5-A-DAY WITH  
HEART  
MATTERS**



# Alcohol and Smoking

- Poor understanding safe drinking
- Stimulant drinks
- Effects of excessive drinking INR
- Recreational drugs



# Pregnancy

- Pregnancy
- Incidence CHD in baby
- NYHA class III or IV, PH, maternal mortality 7%
- Foetal mortality 30% for women in NYHA class IV
- Contraception
- Termination?



# Endocarditis

- Symptoms and change in prophylaxis
- High risk lesions. Dentist.



# Scars

- Scars
- Body image
- Red Cross camouflage make-up



# Risk Taking

Non-adherence

DNA

Sport

Unprotected sex STI

Drugs

Social problems

Depression

Mental health problems



NSF 2006

Tong E and Kools S 2004

# Careers and Employment

Employment advice and support

Only 10% are totally disabled

Intellectual limitations

Isolation and low self esteem

## **National Careers Service**

[www.direct.gov.uk/youngpeople](http://www.direct.gov.uk/youngpeople)

Life Insurance

Mortgage and buying a house

Variable loading

Travel insurance shop around

The logo for the National Careers Service is a blue square with a white diagonal line from the bottom-left corner to the top-right corner. The text "National Careers Service" is written in white, bold, sans-serif font, stacked vertically. The tagline "Helping you take the next step" is written in a smaller, white, sans-serif font below the main text.

**National  
Careers  
Service**

Helping you take  
the next step



# If it does not happen...

Poorly planned transition is associated with risk of non-adherence to treatment

Loss to follow-up

Measurable adverse consequences in terms of morbidity and mortality

Psychological distress

# Lost to follow-up

- 50%-75% patients lost to follow-up
- Reasons for lapse in care x 6
- Lost to follow-up and symptomatic 36%
- Proportion of patients **admitted to A and E** nearly doubled around the time of transition
- Patients must acquire appropriate beliefs about adult care well before transfer.



# How to make it happen

- Set up transition clinics, one a month
- Slightly longer slots Nurse support
- 13-17year olds
- Information in clinic
- BRHC
- Approximately 800 patients age 14 yrs -17yrs on Heartsuite
- Transition clinics all consultants
- CNS support
- Open evening
- Ready steady go



The  
Somerville  
Foundation

Supporting young people and adults  
born with a heart condition

A Guide  
to Adult  
Cardiac Care



# Network

- Young adult clinics
- Network paed transition clinics
- Twice a Year
- CNS
- Database of young people
- Survey
- Staff training



# Goal

- Uninterrupted and co-ordinated transfer to adult services develop skills in self care
- Empower patients to manage their own health care
- Education
- Support family in changing role
- May never happen!

## The Ready Steady Go transition plan - Getting Ready

The medical and nursing team aim to support you as you grow up and gradually help you develop the confidence and skills to take charge of your own healthcare

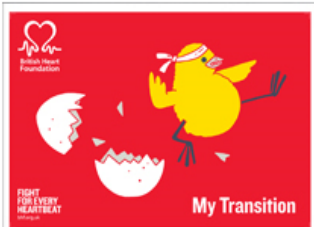


Name: \_\_\_\_\_

Date: \_\_\_\_\_

Knowledge and skills	Yes	I would like some extra advice/help with this	Comment
<b>KNOWLEDGE</b>			
I can describe my condition			
I know when to take my medications, names, doses, how often, etc			
I know who's who in the medical and nursing team.			
I understand the differences between paediatric and adult health care			
I know about resources that offer support for young people with my condition			
<b>SELF ADVOCACY (speaking up for yourself)</b>			
I feel ready to start preparing to be seen alone for part of the clinic visit in the future			
I ask my own questions in clinic			
<b>HEALTH AND LIFESTYLE</b>			
I understand it is important to exercise for my general health and condition			
I understand what appropriate eating means for my general health			
I am aware that my condition can affect how I develop e.g. puberty			
I understand the risks of alcohol, drugs and smoking to my health			
I know where and how I can access information about sexual health			

# Resources



## Picture Your Journey - Making the transition from child to adult care

Pack

English | Published: 06/02/2015



**Resource code:** G690

**Publication for:** Children and young people

**Subject:** Lifestyle advice, Heart conditions

**Age group:** 11-14 years, 14 years and over

**Maximum order quantity:** 20

## HEART CONDITIONS IN YOUNG PEOPLE

The journey from child to adult care

Dealing with teen stress

Healthy eating for young people

Physical activity and young people

Preparing for surgery (videos)

Learning to drive with a heart condition

Sex and relationships

Smoking and heart disease

The effects of drugs on your heart

Effects of alcohol on young people

BHF volunteering for young people

Join [meet@teenheart](mailto:meet@teenheart)

## Going to Uni

Six young people talk about the challenges of going to university and how having a heart condition shouldn't stop you from having a positive experience.



## *You're Welcome quality criteria*

*Making health services young people friendly*

### **Department of Health**

*Quality criteria for young people friendly  
health services*





*National Service Framework for Children,  
Young People and Maternity Services*

## Transition: getting it right for young people

Improving the transition  
of young people with  
long term conditions  
from children's to adult  
health services

← Adult Health Services  
Employment  
Further Education  
↑ Children's Health Clinic  
School

Children's  
Health Clinic  
School

# Improved clinical, educational and social outcomes



# Transition from children's to adults' services for young people using health or social care services

NICE guideline

Published: 24 February 2016


[nice.org.uk/guidance/ng43](https://www.nice.org.uk/guidance/ng43)

The image shows three young people jumping joyfully on a grassy hill. They are captured mid-air, with their arms raised and legs bent. The person on the left is wearing a black and white patterned top and black pants. The person in the center is wearing a black long-sleeved shirt, a black hat, and blue jeans. The person on the right is wearing a red and black striped long-sleeved shirt and blue jeans. The background is a clear blue sky, and the foreground is a lush green grassy hill.

# NSF

- Would like to see young people being supported in education, health, development and well being
- **Young people need to take responsibility for their own health, make informed choices and decisions about their emotional and social development, health and well being**

**THANK YOU!**



questions?