

Transition to Adult Services

Sheena Vernon MSc
Lead Nurse CHD Network
Bristol Heart Institute

Moving to the adult services



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



CHD Standards

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

Standard	Paediatric	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)	Children and young people should be made aware and responsible for their condition from an appropriate developmental age, taking into account special needs.	Immediate
I3(L1)	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.	Immediate
I4(L1)	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.	Immediate
I5(L1)	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.	Immediate
I6(L1)	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.	Immediate

CHD Standards

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Standard	Paediatric	Implementation time scale
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
- Transition
- How do they feel about it?
- How do it
- What happens if we don't do it?
- What can help
- Case studies

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

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
- During **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*

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.

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

- '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)

“Um, I know I had a switch operation [...] off the top of my head, *I’m not really that sure of the details.*” (P4)

“No₁ 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)

“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)

‘The 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 it's 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



Van Deyk, K. et al (2010) AmJC

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



*Moons P et al 2001
Veldtman G et al 2000
Dore A et al 2002*

Tell me what you understand
about your heart condition?

Opening questions?

Compliance

- Medication
- Side effects
- Warfarin
- INR testing



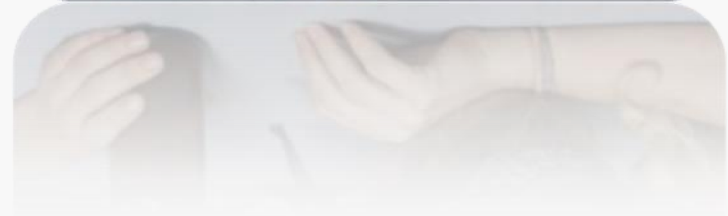
Diet

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



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

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

Life Insurance

Mortgage and buying a house

Variable loading

Travel insurance shop around



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
- Poor social and educational outcomes

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.



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!

	Adult	Implementation timescale
18(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
19(L1)	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.	Immediate

Learning Difficulties

- 1 in 700 born with Downs, 40% will have CHD
- If well prepared, time in hospital is uneventful
- Capacity to consent? Best interest?
- Community team support

*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

You're Welcome quality criteria

Making health services young people friendly



A photograph of three young people jumping joyfully on a grassy hill under a clear blue sky. The person in the center is wearing a black hat and a black long-sleeved shirt, with arms raised high. The person on the left is wearing a black and white patterned shirt and black pants, also with arms raised. The person on the right is wearing a red and black striped long-sleeved shirt and blue jeans, with arms raised. The grass is green and the sky is a solid blue.

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**

Cardiac Youth Worker

Alex Cook

Young people age 16yrs -25 years

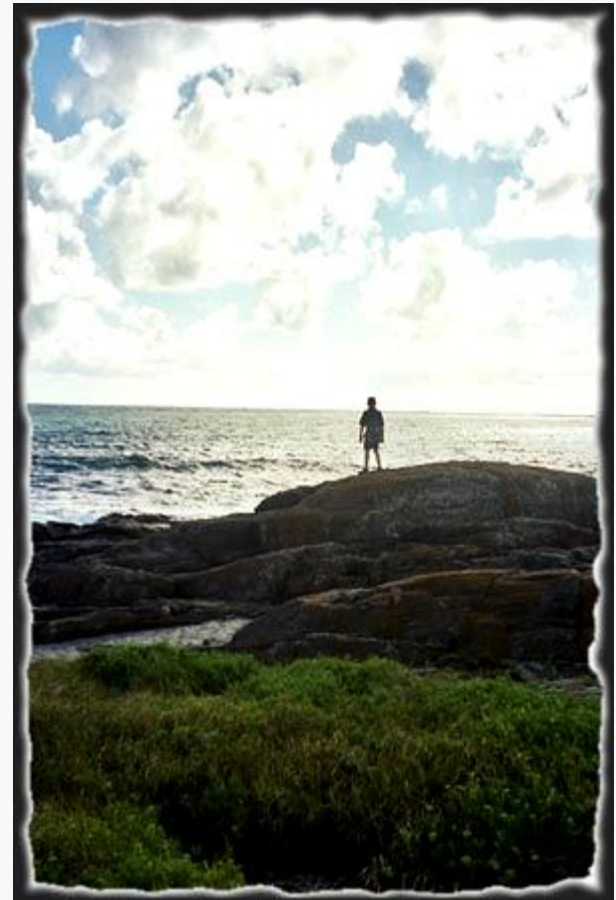
Youth@Heart charity

YP evenings


- Open evenings in BHI every six months with paed team
- LD evening

The Future

- BCH
- Pathway ladder
- YP clinic
- Patient and parent letter, information and visits
- App
- Staff training



THANK YOU!



questions?

International Guidelines

- European Society of Cardiology's guidelines on the “Management of Grown Up Congenital Heart Disease” June 2003
- The British Cardiac Society Working Party on Grown-up congenital heart disease (GUCH). September 2002.
- The 32nd Bethesda conference: Care of the Adult with Congenital Heart Disease JACC Vol 37, 2001.
- The Canadian Cardiovascular Society's Consensus Conference update 2001 update.

Case Studies

What are you going to think
about?

Case 1


Jessica aged 16

- VSD closure, mechanical TVR, PPM
- middle of GCSEs
- promiscuous
- mother bipolar, lives with gran
- never been to adult hospital
- emergency admission with ruptured ovarian cyst and haemorrhage post op Hb 3
- on warfarin 5mgs

Megan aged 18

- HCM, RVOT obs ICD
- Unprotected sex
- Tattoo
- Drinks a lot
- Parents separated
- Atenolol

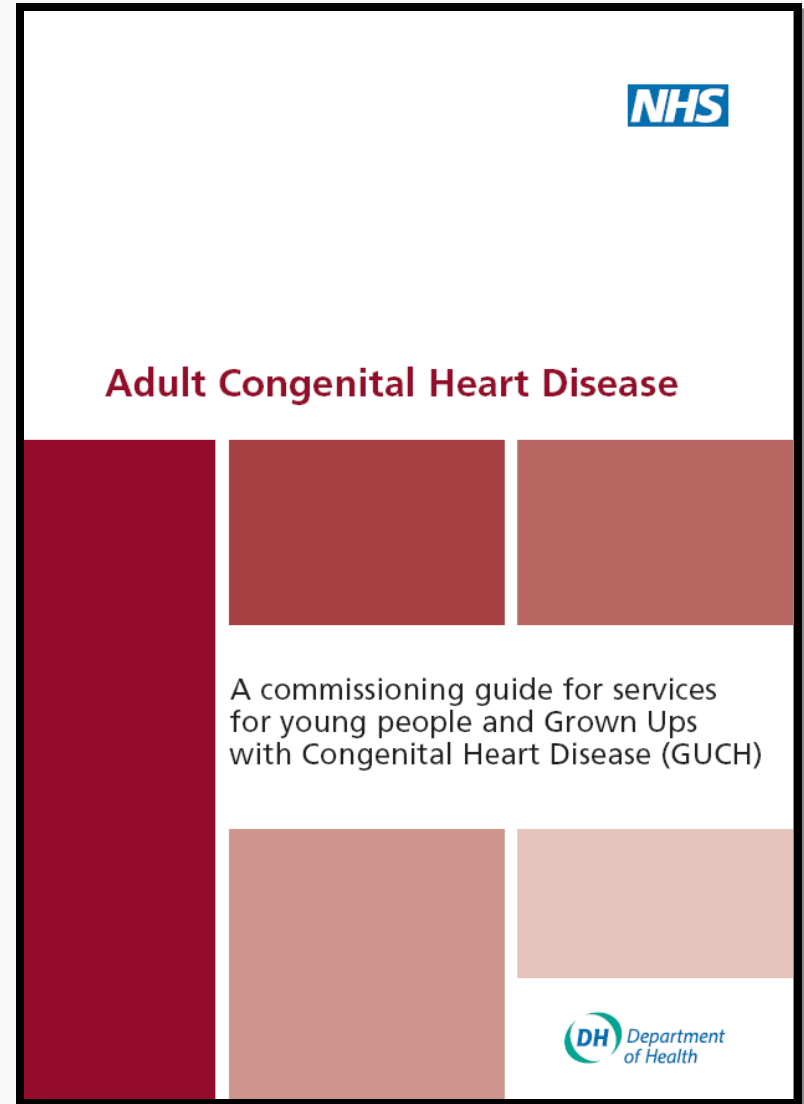
THANK YOU!



questions?

Commissioning guide

- Formal transition from children's to adult service
- Detailed care plan
- CNS main point of contact
- Age of transition negotiated with young person and family, usually completed by age 18yrs.
- Life long follow-up discussed



Issues to discuss

What do we need to discuss
with young people as they
near transfer?

Question?

What do you think it feels like to be moving hospitals?

Give me 5 feelings the patients may have.

