



Transition: The move from paediatric to adult congenital heart disease (CHD) services

This information sheet will inform you about what transitioning from paediatric to adult congenital heart disease (CHD) involves; who to contact for further information; and signposts you to CHD transition support services.

Transitioning to adult CHD services

Transitioning means moving from paediatric congenital heart disease (CHD) services to those provided for adults with CHD.

Any move that involves changing a known medical health team for a new multi-disciplinary team will involve natural feelings of apprehension or even a sense of being out of one's depth.

This 'out of depth' feeling is totally natural and exactly where you're meant to be. Here's why.

Planning before the move to adult services



- We plan our holidays. We plan where we want our children to go to school. And this planning for your child's next move on their CHD journey is going to be of equal help to you as their parent as it will be for your heart child.
- It will allow you to keep ahead of any possible changes occurring at a local service level. And will be of benefit for your child, so that their natural feeling of apprehension can be dealt with successfully.
- Generally, the transition to adult CHD services happens at about 16 years of age.

Transition support days

Some hospitals organise specific events called **Transition Support Days** for young adults soon to be part of their congenital heart disease support services. And these specific events offer a welcome forum to meet other young adults starting on their adult CHD journey.

Transition Support Days provide a safe place to ask questions about health and life-style matters that can be sensitively and clearly discussed by trained health professionals.

Picking up on *un-asked* questions

- You may pick up that your child/young adult has further questions that you think could be addressed by their GP or Cardiac Nurse. And you may feel intuitively that with your permission your son or daughter may want you to initially broach a subject with their GP/Cardiac Nurse.
- Parents have told CHF that they have seen the benefit of letting the health professional know about their young adult's key concerns, and then leaving their young adult alone with their health professional so that they can speak one-to-one with their GP/Cardiac Nurse, while their parent is outside the room.

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Transition Support Health Professionals

The hospital providing adult congenital heart disease (CHD) support may also have a named nurse co-ordinator who may mentor young adults starting on their adult CHD journey.

Children from about 12 or 13 years of age will have a named Cardiac Liaison Nurse with whom they can draw up a **Transition Support Plan**. This will be an important document to revisit at regular intervals to inform both the young adult and their parents about their health condition.



- The agreed plan will inform the young soon to be adult CHD patient about how to manage their symptoms and the networks of support that can be accessed in addition to the adult CHD services offered by the hospital.
- It will be helpful to find out about the Cardiac Liaison Nurses who are especially trained to deal with transition support and if there are specific counselling, psychological or mental health support networks that can be accessed if required at the local hospital/health facility.
- All information that you receive prior to your child's transition to adult congenital heart disease services will be of help.
- It might be useful to create an information hub at home, to keep all the relevant informational resources to hand, so that you can chat about the planned transition with a positive outlook at the times that you will know to be right for your young adult and for yourself as their carer and Number One Advocate.

About this document:

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To inform CHF of a comment or suggestion, please contact us via info@chfed.org.uk or Tel: 0300 561 0065.

Transition Support Networks

These groups and hospitals offer transition support:

Children's Heartbeat Trust - Charity

<https://www.childrensheartbeattrust.org/support-for-young-people/transition/>

Council for disabled children: Transition Information Network

<https://councilfordisabledchildren.org.uk/transition-information-network/about-us>

For Scotland's Disabled Children (fSDC)

<https://www.fsd.org.uk/information/transitions/>

ECHO: Connecting the children's heart community
Organise transition days in collaboration with Evelina London and St Thomas' Hospital, and other London hospitals.

<https://echo-uk.org/resources/transition-days-helping-move-adult-services/>

Freeman Hospital - Newcastle

http://www.newcastle-hospitals.org.uk/services/cardiothoracic_services_childrens-heart-unit_cardiology.aspx

Great Ormond Street Hospital – London

<https://www.gosh.nhs.uk/your-hospital-visit/transition-adult-services>

Heartline Families – Charity

<https://www.heartline.org.uk/register/>

Little Hearts Matter – Charity

<https://www.lhm.org.uk/seeking-support/support-young-members/>

Royal Brompton and Harefield Hospital - London

<https://www.rbht.nhs.uk/our-services/paediatrics/information-for-children/transition-adult-chd-service>

South Wales and South West Congenital Heart Disease Network

<https://www.swswhcd.co.uk>

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Evidence and sources of information for this CHF information sheet can be obtained at:

(1)
CHF resource on Cardiac Staff Teams at Specialist Centres in England and Wales. 2019.
Available at:
<http://www.chfed.org.uk/cardiac-staff/>

(2)
ECHO: Connecting the children's heart community. Organise transition days in collaboration with Evelina London and St Thomas' Hospital, and other London hospitals. 2019. Available at:
<https://echo-uk.org/resources/transition-days-helping-move-adult-services/>

(3)
NHS Congenital Heart Disease: Treatment. 2019. Available at:
<https://www.nhs.uk/conditions/congenital-heart-disease/treatment/>

(4)
South Wales and South West Congenital Heart Disease Network. 2019. Available at:
<https://www.swschd.co.uk>

(5)
The Somerville Foundation
The UK's only charity dedicated solely to supporting adults with CHD. 2019. Available at:
<https://thesf.org.uk/home/>