

Changing Roles

Handing over responsibility for health care to your teen



Understanding your new role.

As your teen begins their journey to transition to adult care, this can raise fears and anxieties around the change in your role as a carer and your teen's ability to cope with the new responsibility placed upon them.

Adolescence is a challenging time with major social, lifestyle, health, emotional, educational and career challenges for the teen to deal with. To support your teen through this period your role will need to shift from manager, to a more hands off, supportive and guiding role. This will help them gain independence over these life challenges, including their own healthcare management.

As a carer of a young person with childhood-onset heart disease, you will have had to manage and navigate the complex care of your child and the healthcare system. By utilising this knowledge and gradually passing the baton to your teen you will help to empower them to take this next step into the adult health care system with confidence.

Transition of care programs aim to help your child learn the skills needed to look after their own care as they make their way to independence. Importantly, this journey will happen with their most valuable mentor – **YOU!**

Sharing the expertise you have gained over the years around your teen's health is invaluable as you coach them towards self-management of their health. Becoming an educator and integral support to your teen during transition will provide change and new challenges for you in your role as a carer. As you go through this significant change in your role it is important that you also look out for your own mental health and seek support if needed.

Remember it is natural to worry!

You are not alone in having concerns and worries about your changing role during transition from paediatric to adult health care.

Below are some common worries identified by other carers of children with chronic health conditions and ways we can reduce the stress around them

“What will I do now I don't have to care for them?” – This is part of the natural cycle of parenting and you will still be there to support when needed, but in a more passive role.

“I don't know if I can trust adult care, they really look after us the children's hospital.” – Adult care will be gradually introduced into the management of your teen so you can both feel confident and comfortable when it is time to transfer across.

“I don't know if my child is mature enough or capable of looking after themselves.” – Transition programs help prepare them to manage their healthcare. It is important that you support them in the process, show belief in them and keep positive.

“I don't know if I can trust my child to keep themselves safe!” – Through education on the transition program you can help them learn all the skills and knowledge they need to keep themselves safe.

“I know they need to be independent, but I feel in control looking after their care and it reduces my stress.” – Independence is an important part of adolescence and they will need to learn self-coping skills to look after not only their health but normal day to day life.

“What if I miss out on information that is not shared when my teen sees the doctors alone?” – The transition process will be staged and patient only consultations gradually introduced, with key information shared and you will remain as their advocate in important decisions around medical care. However, it is important to remember that as your teen becomes an adult, they are entitled to privacy and confidentiality around their health.

Supporting your changing role and wellbeing.

It is essential that you look after your own mental health and well-being as you adjust to your new role. Below are some practical ways to help you cope with this new role.

- If you are feeling uncertain, sad or anxious about your change in role it is important that you let your child's healthcare team know as they can help answer your questions and settle your worries – **this can be at any time during transition.**
- If you are finding coping with the new role really challenging they can help to arrange a counsellor to support you and help you work through your worries.
- Your GP is also another great source of support and can help you find solutions and cope with any problems that emerge. A GP can provide you with information and give you a referral to see a psychologist or other therapist if required. They can work with you to create a Mental Health Care Treatment Plan which can even give free access to services.
- Remember if your feelings change and you need support at any time, it is important to reach out for help.
- By sharing this exciting part of your child's journey as their mentor you will find new purpose and not only help them to transition to self-management but also transition yourself into a new phase of your relationship, building mutual respect and trust.
- Another great way to help you understand your new role is to reach out to others who have gone through the same experience. Support groups and support services can help link you up with others so you can learn from their experiences.

Community supports

HEARTKIDS AUSTRALIA

HeartKids Australia provide access to support services within the CoHD community and can help connect you with others who are on or have recently been through your journey.

By contacting the helpline on 1800 432 785 they can put you in touch with the right kind of support to suit your journey as a carer. The Helpline is available during business hours (9am to 5pm, Monday to Friday). There is also an online form you can fill in outside of these hours and a live chat service to help you find what you need.

CONTACTS

www.heartkids.org.au

You can find more resources under the support and info link

1800 432 785

(9am to 5pm, Monday to Friday)

BEYOND BLUE

Beyond Blue also provide mental health support, information and resources online or by phone. It provides online chat, online forums and a 24/7 Helpline.

www.beyondblue.org.au

1300 22 4636

(24/7 Helpline)

CARERS AUSTRALIA

Carers Australia provide short-term counselling and emotional and psychological support services for carers and their families in each state and territory.



www.carersaustralia.com.au

1800 242 636

ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

For Aboriginal and Torres Strait Islander People Well Mob has a collection of social, emotional and cultural wellbeing online resources.

www.wellmob.org.au

 heartkids.org.au |  1800 432 785 | © HeartKids

This fact sheet was produced as part of the National Action Plan for Childhood Heart Disease Health Professional Education Project with a working group for transition of care comprised of relevant health professionals from the CoHD community along with consumers with lived experience. This document has also been reviewed by the HeartKids Clinical Advisory Committee at the time of publication in March 2024. Clinical information might change after this date. The information in this fact sheet is general. It is not a substitute for medical advice from your doctor. Always talk to your doctor about matters that affect your or your family's health. Got some feedback about our resources? Go to: heartkids.org.au/feedback