



**HeartKids**

# Growing up with a heart condition

Information for young people about transition and how to stay on top of their care.

Between the ages of 12 to 25, young people are moving from childhood to adulthood.

This is an exciting time of transformation. During this time, you will develop the skills and knowledge to manage your own life, including your heart condition.

## What is transition?

Transition is the process of developing the skills you will need to manage your life and health care more independently. The transfer from the children's to the adult health system occurs when you turn 18, but you can start getting ready before then.

Your parents may have made a lot of decisions and arrangements for you when you were younger. As you become a teenager and young adult, you will get the opportunity to start making more decisions for yourself.

This requires a new set of skills, which you will develop over time.



## Why do I need to transition?

The team that treated you in your childhood specialise in treating children. When you become an adult, it is best that you see doctors who are experts in treating adults. They can help you address some of the new questions and needs you may have as an adult.

It is okay to feel sad when leaving your current team. Change can feel scary at first, but this change is an important part of growing up.

Remember that it gets easier as you get used to it.



## How is the adult system different?

One of the main differences in the adult system is that you will be in control of making decisions, not your parents.

Like all changes in life, the new system can take a bit of getting used to. You may want to start practicing some skills before you transfer to the adult system.

### Health care skills:



- **Keeping track of your medical records.** Learn about and organise information on your condition, surgeries, treatments and medications. 
- **Time alone with your doctor.** Get comfortable talking to your doctor about your health without your parents in the room. 
- **Taking responsibility for your own medications.** Learn how and when to take your medications and how to get new prescriptions. 
- **Booking your own appointments.** Learn how to call or email the clinic and book your own appointments. 

## How do I transition?

Transition doesn't happen overnight. It is a gradual process broken up into stages. New responsibilities are introduced slowly. Some hospitals run transition programs that can help you develop your skills and knowledge.

### More information on transition

Access resources including fact sheets and transition readiness checklists.

-  [Royal Children's Hospital Melbourne](#)
-  [Trapeze \(Sydney Children's Hospital Network\)](#)

## Key stages of transition

### INTRODUCTORY PHASE

(12-15 years old)

**Introducing you to transition:** What it is and why it is important.

Young people start learning more about their condition and how to manage it to the best of their ability.



### PREPARATION PHASE

(15-18 years old)

**Practicing some of the tasks you will do on your own when you are an adult.**

Young people will learn about patient confidentiality and may start to have time on their own with their doctor.

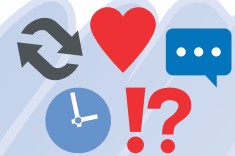


### TRANSFER PHASE

(18-19 years old)

**Assessing how ready you are for transition and addressing any concerns you might have.**

Young people will meet their adult care team. Patient information transfers to the new team.



### EVALUATION PHASE

(6-18 months after transition)

**Providing feedback about the transition process.**

Young people can share their experiences about transition. This can help improve the process for others.



Source: Royal Children's Hospital Melbourne

## Making healthy choices

Having a heart condition doesn't need to stop you from doing the things you want to do. It can mean that sometimes things need a bit more planning.

Living a healthy lifestyle is an important part of taking the next step into adulthood. Read our fact sheets for more information on exercise, travel, alcohol, energy drinks and more.



Your doctor and health care team are there to support you and answer your questions about your condition and transition.

## Talking about mental health

Growing up and transitioning to the adult system is a time of change. It can be stressful at first, but it does get easier.

However, if you start to feel anxious, stressed or down for long periods of time, you might want to talk to someone that you can trust. This might be a youth worker, school counsellor, a friend or family member, or your doctor.

If you don't feel comfortable talking about your mental health when your family is there, you can ask your doctor for a private appointment.

## Mental health support

### Kids Helpline

 1800 55 1800

### headspace

 [headspace.org.au](https://headspace.org.au)

### ReachOut

 [au.reachout.com](https://au.reachout.com)

## References

<sup>1</sup>ROYAL CHILDREN'S HOSPITAL MELBOURNE (2021). "Information for young people transitioning from paediatric to adult health services." Retrieved March 2021. Available: [Online](#).

This fact sheet was reviewed and updated by HeartKids in March 2021. It was endorsed by our Clinical Advisory Committee at the time of publication. 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 health.

## Where to find more information and support

### HeartKids

 [heartkids.org.au](https://heartkids.org.au)

Learn more about CHD and the support HeartKids can offer you.

 MyHeart group

HeartKids' online community for young people (13 to 25 years) with CHD.

 1800 432 785

Call the HeartKids Helpline for support, advice and guidance.

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