

Growing up

with a

heart condition.

A teenager's guide!



HeartKids

**Having genuine chats
with other people
with heart conditions
really empowers and
inspires me.**

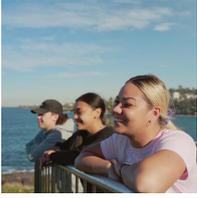
Sam Chung
22 years





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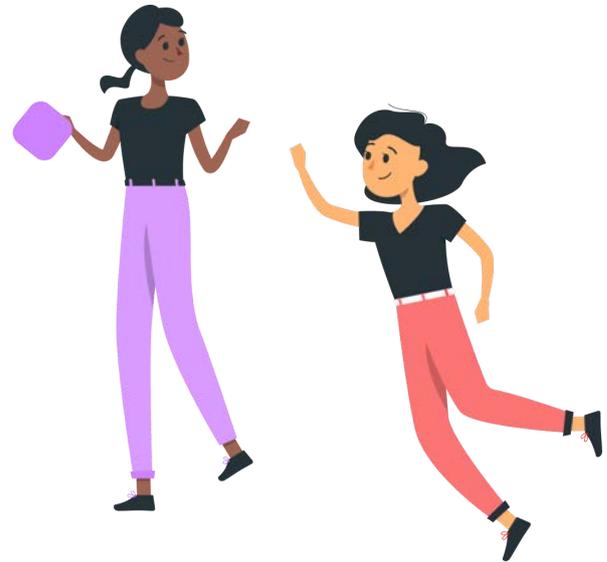
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GROWING UP

With A Heart Condition

Between the ages of 12 to 25, you will be moving from childhood to adulthood. This is an exciting time of transformation. During this time, you will develop the skills and knowledge to start managing your life more independently, including your heart condition.

What is transition?

Transition is the process of getting ready to move to the adult health care system. During transition, you start 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 generally occurs when you turn 18 years old.

How is the adult system different?

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

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

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's 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.



What kinds of skills will I learn?

Your parents may have made a lot of decisions 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.

Some skills include:

- Keeping track of your medical records and information
- Spending time alone with your doctor, talking to them and asking them questions
- Taking responsibility for taking your own medications and renewing your prescriptions
- Booking your own appointments.

How do I move to the adult system?

Some hospitals run programs that can help you develop your skills and knowledge.

Transition to the adult system doesn't happen overnight. New responsibilities are introduced slowly. It's a gradual process broken up into stages.

Key phases of transition

Introductory Phase (12-15 years)

Introducing you to transition. You will start learning more about your condition and how to manage it to the best of your ability.

Preparation Phase (15-18 years)

Practicing the tasks you will do on your own as an adult. You will learn about patient confidentiality and may start having time on your own with doctors.

Transfer Phase (18-19 years)

Assessing how ready you are and addressing any concerns you might have. You will meet your new team and your patient information will transfer across to them.



MENTAL HEALTH

And Your Heart



Mental health is a state of social and emotional wellbeing. It's an important part of your overall health. Feeling good mentally helps you to enjoy life and reach your goals in things like school, work and relationships.

How is my mental health related to my heart?

Growing up with a heart condition, some of the things you experience may have been unique to the people around you.

You may have thought or felt some of the things on this page before. You are not alone. There are over 72,000 people living with childhood heart conditions in Australia.

Mental health, just like our physical health, is something we all need to work at and look after. There are lots of resources and support networks out there to help with this. We have listed lots of support resources at the back of this booklet.

Sometimes I feel different to my friends at school because of my heart

Managing my condition on top of the other responsibilities I have can feel stressful

Sometimes I get anxious about my health and what the future holds

5 Tips To Look After Your Mental Health!



1. Do the things you love

Making time to do the things you enjoy can help to lift your mood and boost your energy levels. Having hobbies can help you cope with stress and connect with people.



If I'm feeling down and out, or anxious about anything, I turn to my support network immediately. For me that's mainly my mum and family.
Kennedy, 22 years

2. Hang with friends and family

Building a network of supportive people around you is one of the best things you can do for your mental health.



The gym helps me focus on regaining my physical strength which makes me feel better emotionally.
Bryanna, 20 years

3. Eat, sleep, move

Eating healthy food, sleeping well and staying active is really important for your mind and body. Talk to your cardiologist about the right amount of exercise for you.



When I am stressed about my Uni workload or just life in general, I like to do jigsaw puzzles to relax and focus on myself.
Alisha, 18 years

4. Connect with others

Talking to other people with a heart condition, who understand your experiences and feelings, can be helpful.



5. Learn about your condition

One of the first steps to taking control of your health is finding out more about what you can do to help it, like making sure you go to your health care appointments.



I listen to music and chill when I'm not feeling so good.
Lily, 16 years

**Teen Camp was one
of the best things I
have ever done.
I made lifelong
friends.**

- Camper from Teen Camp 2020



Teen Camp is a free event for heart teens aged 13-17. Find out more:





EXERCISE

With A Heart Condition

Almost everyone with a childhood heart condition can benefit from exercise. Physically active lifestyles are important. It's about finding a way to be active in a way that is safe and beneficial for you.

5 Benefits of Exercise!

1. Fitness and strength

Exercise improves your cardiorespiratory fitness and muscle strength, allowing you to do more activities.



2. Mental health and happiness

Many studies show that exercise improves mental health and quality of life.



3. Healthy weight and body image

Exercise helps you to maintain a healthy weight, which can also improve self-confidence and body image.



4. Meeting new friends

There are many opportunities to meet new people through community sport or other activities.



5. A healthy heart

Exercise reduces your risk of acquiring cardiovascular problems (like high blood pressure, a stroke or heart attack).



Your doctor or cardiologist can help you find a way to exercise that is safe for you.

I love my scar.

It's my badge of

honour.

Sam Stolberg

Heart adult



ALCOHOL

And Energy Drinks



When you have a heart condition, drinking alcohol or energy drinks might carry extra risk for you. To find out what the risks are for you, talk to your doctor or health care team.

What are the risks of drinking alcohol?

Drinking alcohol carries risks for everyone. Alcohol can affect your body and behaviour. Drinking large amounts of alcohol can affect your mental health. In the longer term, it can also damage important organs like your brain and liver. Young people are more likely to be negatively impacted by alcohol because their brains are still developing.

Can I drink energy drinks?

Energy drinks contain high levels of caffeine. Caffeine is a stimulant. It can make you feel more awake, but it also causes your heart to beat faster. Energy drinks may change your heart rhythm, which can be dangerous if you have a heart condition. For some people, it may be safest to avoid energy drinks.

I have a heart condition.

Can I drink alcohol?

Alcohol affects everyone differently. How it affects you depends on things like your weight, medical conditions, medications, what you have been eating and how quickly you drink. Some people with a heart condition may need to avoid alcohol. In Australia you must be 18 to legally purchase and drink alcohol.



If you are thinking about drinking alcohol for the first time, it's a good idea to talk to your doctor or health care team first. They are there to support you and answer your questions.



PRIVACY

In Health Care

Privacy in a health care situation means that what you tell your doctor or health care provider stays confidential (between you and them). You have a legal right to this privacy.

Will the doctor keep our convo private?

If you are under 18 years of age, a doctor will keep your conversations and appointment notes private if they decide that you can make decisions on your own and that you are not in danger. The best way to know for sure what information will be kept private and what won't be is to ask your doctor at the beginning of the appointment.

How do I talk to my doctor privately?

You can ask your doctor for a confidential appointment (even if you are on your parent's Medicare Card). This is a normal question they are used to hearing. Having time alone with your doctor can also help prepare you for the future when you will be managing your health care independently.

Why is this important?

Research has shown that sometimes young people avoid getting medical help because they fear their parents finding out about it. This could be in relation to sexual health and contraception, mental health, alcohol, or other sensitive topics.

Growing up, you probably attended all your medical appointments with your parent or carer. As you get older, you may have questions you would like to ask your doctor without your family in the room. A private chat gives you the opportunity to do this.



SEX

And Contraception



When thinking about starting a sexual relationship, it's important that you feel in control, and to get all your questions answered. This will help you make the decisions that are right for you.

When should I have sex?

Only you can decide when is the right time to start a sexual relationship. It's about your emotional wellbeing. Most young people find talking to friends or family helpful. Don't be embarrassed to ask questions, it's always good to get the facts!

From a physical point of view, having sex is reasonably strenuous. It takes about the same effort as climbing two flights of stairs. You'll also need to think about contraception and discuss this with your health care team.

What is contraception?

Contraception is used to reduce the chance of pregnancy. It's also called birth control.

Some facts about contraception

- The majority of heart defects do not reduce fertility - you will need to think about and discuss contraception with your doctor, just like other young people do
- CHD does not protect you from sexually transmitted infections (STIs) - you will need condoms to reduce your risk of STIs
- If you are a young woman, the discussion about contraception may start with your GP, but should also involve your cardiologist and possibly a gynaecologist.





TRAVEL

And Travel Insurance

Your heart doesn't have to be a barrier to seeing the world. It may mean you have to think about some extra things before you leave.

Making a Travel Checklist!

Organise travel insurance

Choose a policy that covers your pre-existing heart condition. Take your time to fill out the forms and tell them about your heart. If you don't, they may refuse to pay your claims.



Check for extra vaccinations

Sometimes you will need special vaccinations when you travel to another country. Ask your doctor if you need any extra vaccinations before you go.



Plan your medications

Pack extra medication for your trip in case there is a delay in your travel plans.



Take photos of prescriptions and medications

Have a plan for how you would get more medication at your destination if you lose it while on your trip.



Create a list of health services at your destination

Find out who you can talk to at your destination if you need medical advice.



Talk to your doctor or health care team

They can help you with your travel checklist and plans.





UpBeat

Help to manage
your heart
condition



Developed by
HeartKids



Download our
new app for
heart teens



SUPPORT RESOURCES



Some useful numbers and websites

There is lots of support available to help you on your journey to independence and your transition to the adult health care system.

Transition

Some hospitals run transition programs to help prepare young people for independence. Even if you aren't a patient at these hospitals, they have lots of helpful information you can access.

- Royal Children's Hospital Melbourne rch.org.au/transition
- Sydney Children's Hospital (Trapeze) trapeze.org.au

Mental health

It's okay to need help with your mental health from time to time. In fact, it's an important skill to be able to recognise when you need support and how to get it.

- Kids Helpline 1800 55 1800 (24/7)
- headspace.com
- au.ReachOut.com
- BRAVE program brave4you.psy.uq.edu.au

HeartKids

Other fact sheets, videos and resources to help you with transition.

- HeartKids Helpline 1800 432 785
- Podcast: From the Heart (Search on Spotify or Apple Podcasts)
- Resources (fact sheets and videos) heartkids.org.au/resources
- Teen events calendar heartkids.org.au/events
- Instagram: HeartKids youthzone @youthzone_heartkids
- UpBeat teen transition app: Search UpBeat on the App Store

LGBTQIA+

If you have questions about your sexuality or gender identity, or are just looking for information about the LGBTQIA+ community, these resources may be useful.

- Minus18.org.au
- QLife.org.au