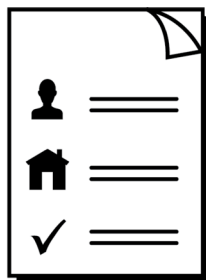


Growing up with a heart condition



Easy Read

About this fact sheet



This fact sheet is from HeartKids.

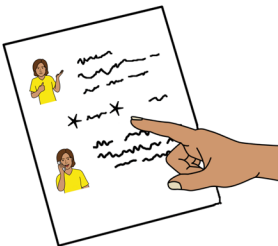


This fact sheet is written in a way that is easy to understand.



You can read more information about HeartKids on our website.

Visit heartkids.org.au



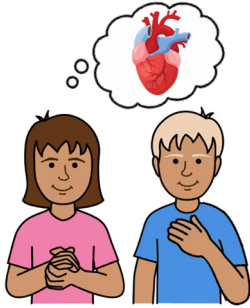
We add a star before and after ***hard words***. Then we explain what the words mean.



You can ask someone to help you read and understand this fact sheet.



Contact information is at the end of this fact sheet.



Childhood onset heart disease

We help people with

childhood onset heart disease or COHD.



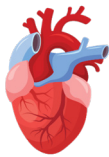
COHD means a ***heart condition*** that starts

- before you are born

or



- when you are young.



A heart condition means your heart works differently to the way it should.



Most children with COHD grow up to live normal lives.

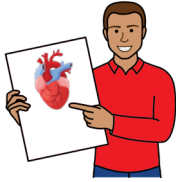
Growing up with a heart condition



It is important to stay healthy as you get older.

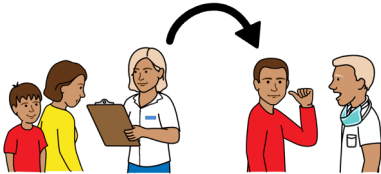


From the age of 12 to 25 you go from being a child to an adult.

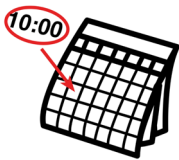


As you get older you can do more things by yourself.

For example, manage your own health care.



You will go from child to adult health services when you turn 18.



For example, you may need to

- book your own appointments



- know when to take your own medicine.



The adult health care system is different to the system for children and young people.



The main differences are

- your parents do not make decisions for you



- your doctors treat adults.



It can be hard to manage new things as you get older but it will get easier.

How do you move to adult health services?



Some hospitals have programs that help you understand the changes.



There are 3 steps when you move to adult health services.

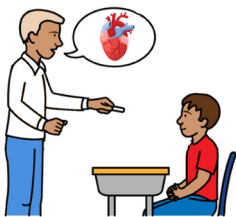
Step 1. *Introduction*



Introduction means you start.

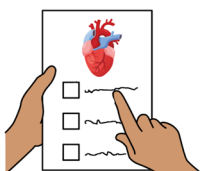


Introduction happens when you are 12 to 15 years old.

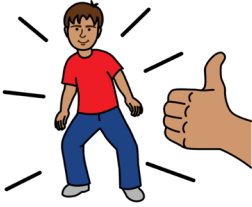


You will learn more about

- your heart condition
- how to manage your heart condition.



Step 2. *Preparation*



Preparation means you get ready.



Preparation happens when you are
15 to 18 years old.

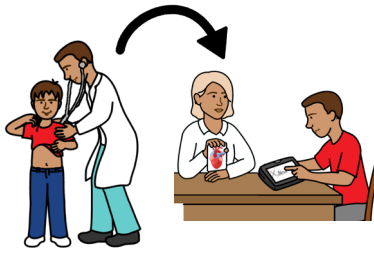


You will practice things you need to do on
your own.



You might see your doctor on your own.

Step 3. *Transfer*



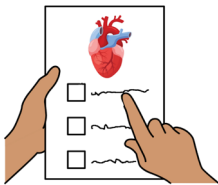
Transfer means you move to the new adult system.



Transfer happens when you are 18 to 19 years old.



You will meet your new team of doctors and healthcare workers.



Your new doctors will get your health information.

Mental health



Good ***mental health*** is important for you to enjoy life and reach your goals.



Mental health means how you feel about yourself and your life.



Everyone has times when they feel

- sad



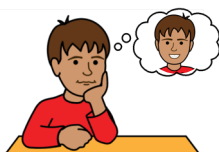
- angry



- stressed.



When the feelings do not go away you may need support.

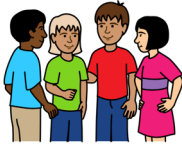


There are things you can do to look after your mental health.



You can

- make time to do things you enjoy



- spend time with friends and family.

You can stay healthy.

For example



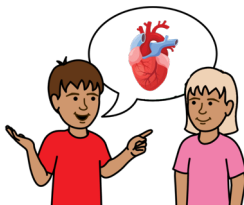
- eat healthy food



- get enough sleep



- do regular exercise.



You can learn from other people with a heart condition.



You can find more information about your heart condition.

HeartKids Teen Camp



Teen Camp is for 13 to 17 year olds with a heart condition.

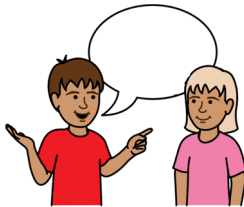


Teen Camp is free.



Teen Camp can help you

- make friends with people who live with a heart condition



- talk about how you feel



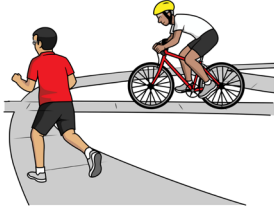
- have fun and learn new skills.



For more information about Teen Camp go to our website.

heartkids.org.au/page/169/teen-camps

Exercise



Most people with childhood onset heart disease can exercise.



It is important to stay healthy.



Find a way to stay active that is safe for you and your heart condition.



Some people have good heart function and can exercise in different ways.



Other people have more heart problems and need to take care when they exercise.



Talk to your doctor about your heart condition and what exercise is best for you.

How exercise can help



Exercise is good for

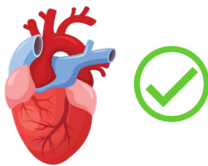
- your mental health and happiness



- your physical health
 - for example, your strength.



Exercise can help you make new friends.

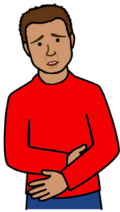


When you exercise it helps your heart work well.

Alcohol and energy drinks



If you drink alcohol or energy drinks it can affect your heart condition.



Alcohol can affect

- your body

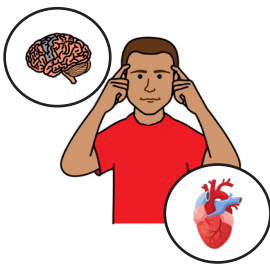


- your behaviour.



If you drink a lot of alcohol it can

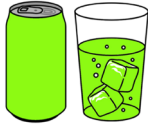
- affect your mental health



- damage parts of your body
 - for example, your heart and brain.



Some people with a heart condition should not drink alcohol.



Energy drinks have a lot of ***caffeine***.



Caffeine makes parts of your body work faster and makes you feel more awake.



Energy drinks can make your heart beat faster which is not good if you have a heart condition.



Some people with a heart condition should not drink energy drinks.



You can talk to your doctor about how alcohol and energy drinks can affect you and your heart condition.

Privacy



Your doctor will **not** share your private information.



Doctors follow the laws about privacy.



If you are under 18 your doctor will keep your information private if they think you can make choices on your own.



You can ask your doctor for a private meeting even if your parents take you to appointments.

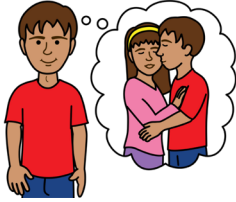


You might ask your doctor for a private meeting if you have questions you do not want to ask your parents.

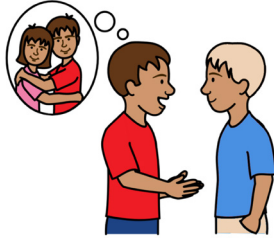


For example, questions about sex or mental health.

Sex and contraception



Only you can decide if you want to start having sex.



It can help to talk about relationships with someone you trust.



When you have sex your body can use lots of energy.



If you have a heart condition you need to think about how this might affect your body.



When you have sex you need to think about ***contraception***.



Contraception means you have less risk of

- pregnancy



- getting sexually transmitted infections or STIs.



There are different types of contraception.



You can talk to your doctor about the best contraception for you.

Travel



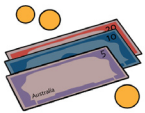
It is ok to travel when you have a heart condition.



You might have to think about some things before you leave.



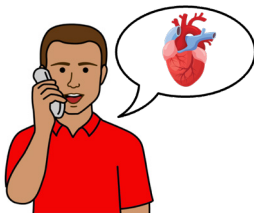
Buy ***travel insurance***.



Travel insurance helps get your money back if there are problems with your travel plans.



For example, if you lose your bags or you go to hospital overseas.



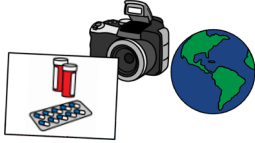
Make sure you tell the travel insurance company about your heart condition before you travel.



Ask your doctor if you need special medicine before you travel to another country.



Pack extra medicine for your heart condition.



Take photos of your medicine in case you need to get more when you are in another country.



Find out where the hospitals and healthcare services are.



You can talk to your doctor about how to manage your heart condition when you travel.



More information

For more information or support contact HeartKids.

Call 1800 432 785

You can contact us from 9 am to 5 pm
Monday to Friday.

Website heartkids.org.au

Support to transition to adult services

Royal Children's Hospital Melbourne.

Website rch.org.au/transition

Sydney Children's Hospital
Trapeze transition program.

Website trapeze.org.au



HeartKids

HeartKids helpline



Call 1800 432 785



Website – resources heartkids.org.au

Website – events heartkids.org.au



Listen to the podcast called From the Heart.

Search on Spotify or Apple podcasts.



Get UpBeat for your phone. An app for teenagers with a heart condition.

heartkids.org.au/page/217/upbeat



HeartKids youthzone on Instagram.

Search @youthzone_heartkids

Support for your mental health



ReachOut

Website au.reachout.com



Kids Helpline

Call 1800 551 800

Website kidshelpline.com.au



headspace

National Youth Mental Health Foundation

Call 1800 650 890

Website headspace.org.au



The BRAVE Program

Website brave4you.psy.uq.edu.au



Support for the ***LGBTQIA+*** community

LGBTQIA+ is a way to show sexual and ***gender identities*** and bodies in the community.

Gender identity is how you feel about who you are as a person.

It is not about your body being male or female.

Website [Minus18.org.au](https://minus18.org.au)

Website [QLife.org.au](https://qlife.org.au)

Help to speak and listen



If you need help to speak or listen, the National Relay Service can help you make a call.



Call 1800 555 660



Website accesshub.gov.au/nrs-helpdesk

Help in your language



If you need help with other languages, contact the Translating and Interpreting Service.



Call 131 450



Website tisnational.gov.au

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