

Educating and preparing your teen for transition to adult care



Introduction

As your teen journeys towards becoming young adult, they will be embarking on new challenges such as leaving school, getting a job, and going on to further education. They will need to learn how to make important decisions around their lives, health and well-being through discussion and mentoring from family, friends and relevant professionals.

Transition of care is an important process to get your teen ready to self-manage their healthcare as move towards independency. This is a time when they will learn new skills and gain knowledge around their health and health management, as well as gaining confidence and self-belief that they can achieve their goals. They will be guided through the process by the healthcare team, peers, family, friends and, importantly, you!

As the person who has looked after their care and health up to now, you are an expert who can help teach and guide them towards the skills and information they need. Teaching can be tricky so we have prepared this document to help guide you on what they need to know and how to approach this.

Like any new task or job this can seem difficult or even overwhelming at first, but if you break down the tasks and the learning into small chunks it will seem a lot less scary. Because we are beginning this process well before your teen begins adult care it gives you and them lots of time to learn and practice the skills they will need. It can be a lot of fun, and sharing knowledge can help build trust and strengthen your relationship. We are sure your young person will surprise you with their capacity to learn, so keep an open mind to their abilities and remember to stay positive about what they can achieve, avoid negative statements and concentrate on the wins you have together.

Encouraging your teen to take more control of their health, to the best of their ability, will help them in the future. This may feel a bit uncomfortable at first as you have been the one making decisions and organising their health care. Parenting an adolescent is a time for letting go of control, balanced with stepping in when needed. Having to say goodbye to your paediatric team at the children's hospital and/or your local paediatrician can sometimes lead to worry for parents/carers. Planning and preparing for this transition can help reduce anxiety and stress.

Neurodevelopmental considerations

Many children with childhood-onset heart disease (CoHD) may be impacted by neurodevelopmental problems. This can mean that they are affected by developmental, behavioural, and psychological difficulties which can lead to developmental disability, delay and learning difficulties.

There are 2 types of neurodevelopmental issues:

Developmental disability

A limitation or disability of cognitive function of the brain (sensing, thinking, feeling, judging and perceiving) or the way the brain handles emotion, behaviour and learning. It can also be physically limiting.

Developmental delay

Development, physical and mental skills may not be at the same level as other children of the same age.

If your child has neurodevelopmental problems it may mean that the learning program detailed in this document needs to be adjusted. This may mean the timings of education may have to be delayed to suit their individual needs, or if they are to remain in your care as an adult that some of the education is not necessary or appropriate. **If this is the case please discuss this further with your healthcare team.**

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Learning together

Follow the steps below and have fun helping to your teen become a young independent adult!

STEP 1

Learn about transition of care and what it means for you and your child. The healthcare team should have provided you with a handout!

STEP 2

Check your knowledge! The healthcare team should provide you with a **checklist** to find out what you know about your young adults' condition and management. You will be surprised how much you already know. If you have any gaps they will be able to help you find the info you need. We have also provided lots of resources in the lesson plan to help you support your teen and learn whilst you teach.

STEP 3

Learn about **self-efficacy**, why it is important in the development of your teen and how you can help them (and you!) build it. The healthcare team should have provided you with a handout!

STEP 4

Find out what your teen already knows about their condition. Get them to fill out a **checklist** on their knowledge, the healthcare team will provide you with this. Once you have completed it will give you an idea of what subjects you need to work on together and what they may already have a head start on!

STEP 5

Start to make your way through the **lessons** in this program together and try and achieve the **goals** outlined. We have included some handy tips, teaching activities and some useful resources. Getting them involved with peers who are going through the same journey is a great way of helping them learn and build confidence. Most importantly, getting them to practice the skills outlined will help them relate their learning to the real world and this will help it stick and move them towards independence. We have sequenced the lessons to help build their skills and knowledge appropriately and have provided suggested age guides for each lesson.

IMPORTANT

Do not try and do all these lessons at once! Schedule in a session each week/month and work through one lesson at a time. Some of them you will keep revisiting as a natural part of the process of transition. Keep the lessons around 30-60 minutes in length so you can both keep focus and enjoy the learning and time together.

Talk to your teen, in age-appropriate ways, about his or her heart defect.

It is important to start to share openly the facts around their CoHD and not to hide information. Discuss and provide information about their heart defect.

Teaching activities and pointers!

- Share the name of the defect. Some congenital heart disease (CHD) names are tough, even for adults, but helping your adolescent learn about their CoHD will help with proper lifelong care.
- Learn how the normal heart works.
- Get them to draw a picture of a normal heart and then do the same for their heart defect. This will help them understand more about the function of their own heart.
- Work through how their CoHD affects their heart function and what impacts that will have on them now and in the future.
- After you have started to share this information, practice getting them to tell you about their condition.

Learning goals

You start to share information on their health and talk to them as an equal around their health and well-being.

They learn about their own heart condition in more detail and can recall and share this information when questioned on it.

They should be able to draw what their heart defect looks like.

This is an important first step in the journey for both of you!

Resources to help you teach

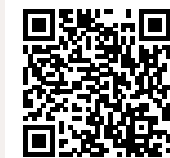
This QR code links to information on heart defects and is produced by the team at the Royal Melbourne Hospital.



QR code for a video on normal heart function.



These two QR codes link to further information about congenital and acquired heart disease provided by HeartKids.



Talk about their health history.

After lesson 1 your teen should have started to learn about their heart condition, but now we can expand this learning around any other health conditions they have, past and future surgeries, and any other relevant health information that can help them in the management of their health.

Not all the activities below may be relevant to your teen.

Teaching activities and pointers!

- Recap on their own CoHD.
- Discuss and describe any other health conditions or disabilities that they have.
- They need to know their height, weight and date of birth (D.O.B.). You could all do this together as a family to make it fun and check it at regular intervals.
- Describe and provide the date of surgeries they have had in the past, as well as any surgeries that they will need in the future.
- Describe any medical devices they have fitted and the date they were implanted and what they are used for. If replacement dates apply for devices these should also be shared.
- Describe any other medical procedures they have had or will need in the future.
- They should also know about any allergies that they have and how they need to manage them. For example, if they are allergic to penicillin they need to know about the importance of sharing this information with healthcare professionals, so they aren't administered any during hospital visits.
- As part of the learning you can get them to log all this information in their personal health care record. The UpBeat App from HeartKids is an excellent tool for this (**see lesson 3**).

Learning goals

They should be able to name and describe their condition or disability, surgeries they have had, and any procedures and surgeries they will need in the future.

They should know their height, weight and D.O.B.

They should know about their allergies and be able to manage them.

They should have organised this information in a way so that they will be able to find it again easily when needed.

Resources to help you teach

The past health history that you have kept will be an excellent resource. If you are unsure of any details contact your health team to find the missing information.

Organising their own health information.

Now your teen has begun to learn about their CoHD it is important that they can find and access the information that is crucial for their own health management. There are many ways to manage and store this information however, there is a transition App that is purpose built for Australia that has been created by HeartKids, called **UpBeat**.

HeartKids partnered with an app development agency and an advisory group which consisted of teens with CoHD from around the country, as well a multidisciplinary group of clinicians from five major hospitals.

The UpBeat app only stores the information locally on your teen's phone and does not track data, so their privacy is completely respected and no data is shared!

More information for you as a carer is provided in the resource section.

Teaching activities and pointers!

- Download the app (see resources).

If your teen does not have access to a mobile phone, a simple solution such as a paper diary to write in can also help them organise this information.

- You can populate the information in the app together, but let them lead. The app is great at stepping you through the process. It is also great chance to revisit learning around their condition and management. Start working on putting in the following info:
 - Condition and surgeries
 - Medication and equipment
 - Health team contacts/emergency contacts
 - Health cards
 - Allergies
- Immunisations
- Notes for any other information that is relevant
- Once it is populated make it a good practice to update the information after every visit to their health team or if any other relevant information changes.
- Practice getting them to find and share some information from their record such as the date of their last surgery or the contact number for their GP.
- There is also an info hub for them to explore to help them learn more about their condition and transition. They can watch videos of other people on the same journey and discover lots of other amazing resources.
- It is now their responsibility to keep the record up to date

Learning goals

They should have all the information about their condition organised and easily accessible and should be able to easily find, recall and share this information when asked.

Check their work on logging the information by asking them to show you their surgical history (if relevant) or current medications.

Get them to use this information when they attend medical appointments and encourage them to add in new information when they get it – this can be fun and really empowering and will help them on their journey to self-management.

Resources to help you teach

There is more info available on the HeartKids website for you as a carer which can be found via this QR code.



To download UpBeat your teen can search UpBeat by HeartKids in the app store, or use these QR links.



How to document and keep track of appointments.

This is an important skill that has been made a lot easier through electronic calendars.

Teaching activities and pointers!

- If your teen has a smart phone take some time together to work out how to add appointments to their calendar. Most phones will have a calendar feature that they can use to easily set up appointment reminders and alarms.
- Similarly, most email providers offer this as a feature as well if that works better for them or if they don't have access to a smart phone.
- Even a traditional paper calendar can work if you do not have good IT access.
- Get them to populate any upcoming appointments into the calendar including, dentist appointments or even other fun activities or birthdays that they have on coming up so that they become comfortable with the technology and process.
- Make sure they document relevant information such as addresses and contact names and phone numbers.
- Do one or two appointments with them and then get them to do a couple on their own. If you don't have any appointments coming up just make up a few times and dates and get them to practice that way.

Learning goals

The young adult will be able to independently add appointments to their diary and set up reminders and alarms. They will be able to notify you when they have their next appointment.

Resources to help you teach

No additional resources are required for this lesson.

Learning about Medications.

It is important that your teen not only knows the names of their medications, but also the reason for taking each medication, potential side effects, and how to get refills. They should also know what happens if they don't take the medication, the dosage for each and the appropriate time to take medications (i.e. after meals) for each.

Teaching activities and pointers!

- Work through their medications together and learn about how to find information on them, dosage, side effects and any other specific considerations such as whether medications are to be taken with food, or may cause drowsiness etc.
- They should be able to tell you the reason for taking all their medications.
- Get them to log this information in the UpBeat App or their diary.
- Once they have learnt about their medications it is important to start to give them the responsibility for taking them each day. It is OK to oversee this initially, but put the onus on them to initiate it and devise a system for recalling information. Gradually reduce your supervision as they get into the routine.
- You should also make them responsible for monitoring when medications are getting low and getting repeat prescriptions filled before they run out. Again, share your system with them and gradually move them towards independence.

Learning goals

They can recall names, dosages, potential side effects, how to get refills and what the consequences are if they don't take medications.

They should be responsible for the management and taking of their own medications.

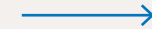
To help them remember this information you can utilise the UpBeat App/Diary as a place to document and store medications.

Reminders can also be set up in calendars to help with remembering to get repeat prescriptions.

By the age of 16 they should be responsible for all aspects of their medication management including getting scripts filled and repeats when needed.

Resources to help you teach

This is a QR link to the Australian Department of Health and Age Care's guide to the safe use of medications which you can use to help to educate your young adult.



Making health care appointments.

Teach your teen how to make appointments for their medical care.

Do this together initially but then move towards supporting them when they need to make an appointment, with the goal of eventually letting them do it independently.

Teaching activities and pointers!

- Make sure that they understand the need for a current referral to see a specialist doctor and how to source one from their GP.
- They will also need to know who it is appropriate to contact to make appointments depending on which health care professional they need to see.
- Making GP and dentist appointments are a great way to start practicing this skill.
- Don't forget to help them put these into their calendar system and set up reminders so that they can remember to keep these appointments.
- Make sure they have the relevant contacts clearly logged for the health care professionals they need to make appointments with.

Learning goals

They will understand the importance of medical appointment scheduling and be able to do this initially with assistance before progressing to independence.

Resources to help you teach

Remember to log important information in their electronic /paper diary and the UpBeat App.

Involve your teen in their medical care.

Now your teen has begun to learn about their health and CoHD it is important to start to involve them in the management of their own care.

Teaching activities and pointers!

- Talk through typical signs and symptoms that they may experience with their health condition and help them understand what they mean and how to manage them. It is crucial they understand the warning signs for when they need to escalate care and contact their health professionals.
- When they need to escalate care they need to know who it is appropriate to do so with and should have those contacts readily available.
- Encourage your teen from an early age to ask the cardiologist and other doctors questions. This will help them feel more empowered and in control, and that confidence will continue into adulthood.
- Start by getting your teen in the practice of writing down questions before appointments – you can do this together at first. For example, they might be interested in knowing what kind of exercise is safe, if they might need any more surgery or have questions about the side effects of their medications.
- This is a lesson for you! Parents and caregivers often answer out of habit, stop yourself from doing this and let your child answer questions.

Learning goals

Your teen will take the lead in answering and asking questions at their medical appointments, with the goal of eventually spending time independently with the health care team before they are transferred to adult care.

They should understand typical signs and symptoms of their condition, what they mean and when to escalate care and, importantly, who they should do that with.

Remember you will still be given an opportunity to voice your concerns too, but it is important to let them answer and ask questions for themselves as this helps build up their self-efficacy.

Resources to help you teach

This is a QR link to a fantastic resource on transitioning to adulthood produced by Children's Health QLD. There is a great section on health care management for your teen to work through with you.



Getting medical help and emergency care.

This is an extension of the previous lessons in talking charge of their care. It is important if they are unwell or need help that they know who to contact and chat with.

Teaching activities and pointers!

- Make sure they understand how to contact the care team, and how important it is for your teen to ask questions until they have their concerns answered.
- They also need to understand all the information they need to escalate care if they are unwell. They need to know when and how to seek emergency care, including the best place for them to get emergency care as an adult.
- Go through important warning signs that may mean that they need to seek urgent care as opposed to less urgent routine care.
- They should know the appropriate people to contact and have the emergency numbers they need in the event of an emergency. If you are not clear on this raise this as soon as possible with your managing team or GP and they will be able to give you guidance.

Learning goals

Your teen will know who, why and when to seek medical help and how to ask appropriate questions.

They will have all relevant contacts stored using their chosen organisation method.

Resources to help you teach

No additional resources are required for this lesson.

Helping your young adult find a trusted GP.

You may already have a GP in place that you see with your teen. However, it is important that they feel comfortable with them and you should have a discussion around whether they trust and get along with their GP.

Remember, as we get older we may want to see a doctor we can relate to easily and this may just be as simple as wanting to see a doctor who is the same sex, religion or ethnic background. Hopefully your teen will build a strong, long-term relationship with their chosen GP and be able to feel comfortable with them and trust that they have their best interests at heart.

GPs are essential in helping keep your teen linked into cardiac care and help in looking after their general well-being, managing other health care and mental health problems. The longer the relationship, the better the understanding they will have of your young adults complex health condition.

Teaching activities and pointers!

- Ask your teen if they are happy with the current GP they have and if they feel comfortable with them as their doctor as they get older. Try and identify what they like and don't like. They may prefer a doctor who is the same sex or who is younger or of the same ethnic/religious background. Take time to work out what would make them feel comfortable.
- If you don't have a GP in place currently or need to change GP it is essential that you find one as soon as possible that your young adult likes and trusts.
- Once you have a GP selected don't forget to document all their contact details with your young adult so they have them at hand when they need them!
- Your teen also needs to understand the importance of the GP in writing a referral every 12 months for their specialist cardiac care and any other ongoing care they may receive from other specialities.
- It is also important for them to understand all the services that a GP can provide – work through the resource provided.
- Remember, it is also important to let them lead the consultations and answer questions and spend time with the doctor alone to build their skills and discuss things that might be sensitive or private.

Learning goals

Find a GP that your teen is comfortable with and start building that relationship.

Your teen should also know what other things a GP can help them with as well as their CoHD.

They should have their contact details and begin to make appointments with them.

They should begin to see the GP alone for part of the consultation ASAP to build independence and self- efficacy.

Resources to help you teach

Health Direct has a great website to help you find a GP if you don't have one. It also has great information on all the things that a GP can help you with as a patient. Have a look at this together with your young adult. This is a QR link to the website.



Teen and young adult general health and wellbeing.

The subjects covered in this lesson are:

- Sexual health, family planning, contraception, and genetic considerations.
- Exercise and body image
- Drugs and alcohol
- Mental health

Some of these topics may feel uncomfortable to talk about at first, but starting to learn about them and the implications for their CoHD is crucial. Starting early is advised to help your teen make the best-informed choices for themselves. Remember, peer pressure is a big factor in a teen's life and being aware of the consequences for their actions on their health is crucial, particularly in the setting of CoHD. This also highlights the importance of having a GP they can trust and turn to for advice as they face these difficult challenges.

Teaching activities and pointers!

- There is a lot to cover here so it is probably a good idea to chunk this into several lessons. Use the resources provided to guide you.
- We have provided lots of fantastic resources that cover these topics in depth including factsheets and podcasts as well as booklets that have more info.
- For each of the topics it is important that they understand the implications of how their CoHD will impact on the topic in question.
- You may want to get your teen to go away and learn about these topics on their own through the resources we provided. Get them to write down questions they would like answered that come up as part of their learning.
- Many questions may need to be answered by health professionals but you should be able to help them with most of them. Use this as a starting point to discuss the topics and get them thinking about the implications of each for them. Any questions that you can't answer get them to write them down and ask them at their next healthcare appointment.
- There may be even questions that they have that they might not want to share even with you and want to address directly with the healthcare team; encourage them to do this.
- GPs are excellent supports in this area, so encourage your teen to make an appointment to discuss any queries or worries they have with them.
- Get them to log any useful numbers and supports in their UpBeat App so they can find them easily again and access them when needed.

Learning goals

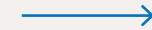
Start your young adult thinking about important wider health issues and get them to have questions ready for their next health care appointment.

They should understand and be able to recall the impacts of the sexual health, drugs and alcohol, mental health and exercise on their specific CoHD.

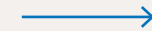
Resources to help you teach

Below are QR links to some great supportive resources around general health and wellbeing provided by HeartKids and Child Health QLD. These are in the form of factsheets, podcasts and booklets.

The **From the Heart** podcasts are with CoHD community members and health experts who discuss many different topics related to the health and wellbeing of people living with CoHD.



There is also a link to an excellent resource produced by Children's Health Queensland on transitioning to adulthood, which although not specifically for CoHD, covers all the considerations your teen will encounter on their journey.



There is also a great booklet for your teen from HeartKids which covers all these topics and lots of additional relevant factsheets.



Education and careers.

It is good to start to consider the impacts of their CoHD on future plans around careers and education. CoHD will not restrict most young adults but there may be considerations for some individuals around suitable careers, and this should be discussed so that educational pathways are in alignment with career choices.

Teaching activities and pointers!

- If you are aware of any restrictions to careers openly discuss this with your teen. They may not impact on what they want to do, but certain jobs such as the armed forces may have restrictions.
- Discuss what interests they have and the kind of jobs they would like. They may not know yet but if they have clear ideas then they will need to start planning the educational route that they need to take.
- Get them to prepare questions for the cardiac team around how any restrictions may impact careers.
- If available, they could contact the school's career advisor who could help them find a pathway to achieve their goals.

Work through the "your career" find a career online tool in the resources section as this can help them discover careers that they might be interested in.

Learning goals

The teen understands any impacts on future employment from their CoHD and is beginning to consider suitable options and plan their educational pathway to achieving their goal.

Resources to help you teach

There is some good general careers advice which you can find using these QR codes.



Medicare Card – what are they for and how to acquire their own.

Understanding what the Medicare Card is used for and the importance of carrying it is the key message. This again is a way of getting ready to be independent by understanding the importance of the Medicare system in health.

Teaching activities and pointers!

- Explain what the Medicare Card is used for and why it is important to carry one, the resources provided are helpful here.
- Initially, they will be on your card and they should be prompted to use your card at appointments. They can also store an image of this in UpBeat for safe keeping and easy access on their phone.
- Once they reach the age of 15 years they are entitled to their own Medicare Card. Get them to go through the process to acquire one of their own and once they have it they can take it with them to appointments (it can also be stored as a photo on the UpBeat App). You can also now get a digital version of the card. The resource provided helps with this process. Work through this together and explain the importance of the card for health care.
- Make sure when you go to medical appointments that your young adult is responsible for providing their Medicare details when required.

Learning goals

They can set up their own access to Medicare and know the importance of having their cards information with them for health care visits.

Resources to help you teach

You can find how get their own card together on the Services Australia website which you can find using the QR code below. Work through this together and explain the importance of the card for health care.



Health Care Card – what are they for and how to acquire their own.

It is important that your teen understands how to acquire a Health Care Card and what its role is in supporting their care. Currently all eligible Australians should receive one but it is important for them to understand when they are eligible to receive one and what this card supports and funds. Remember, even if you are not currently eligible your teen may require this support in the future.

Teaching activities and pointers!

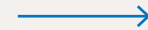
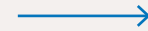
- Explain what the Health Care Card is used for and why it is important to carry one, the resources provided are helpful here.
- Initially they will be on your card but they should be responsible for using your card at appointments. They can also store an image of this in UpBeat for safe keeping and easy access on their phone.
- Once they reach the age of 16 years they may be entitled to their own Health Care Card if they meet certain criteria. In theory, they should be automatically sent out a card if they are eligible but it is a good exercise to look at the eligibility criteria just in case this doesn't happen! Once they have it they can take it with them to appointments (or accessed as a stored photo on the UpBeat App). The resources provided help with this process. Work through this together and explain the importance of the card for health care.
- Make sure when you go to medical appointments that your teen is responsible for providing the Health Care Card details when required.

Learning goals

They understand the role of the Health Care Card in supporting their care and the criteria for eligibility.

Resources to help you teach

These are QR links to the Services Australia and the Department of Social Services website so you can learn more together.



Get them involved with others experiencing the same journey.

Getting your teen to learn from others going through the same experience is essential in building their self-belief and confidence. If they see others succeeding in the tasks they are undertaking they will draw inspiration and start to achieve their goals more quickly. They will also build a social network who can help support them through tougher times through making friendships. This is great for their general development and their mental health.

Teaching activities and pointers!

- Encourage your teen to engage with others who are on the same journey as themselves. HeartKids are an advocacy group that offer specific supports for the CoHD community in this space. One of the great opportunities that HeartKids provide to help build your teen's independence are **Teen Camps**. The camps and events provide an opportunity for young people aged between **13-17** years with a heart condition to connect with others experiencing a similar journey, share stories and develop new friendships. The activities encourage young people to increase their level of independence, build their health care skills, and develop self-confidence. It really can be life changing. This approach has been shown to help build engagement and skills in helping teens move to managing their own health care.
- Look into the teen camps together using the resource provided and if your teen has questions they can discuss them with the camp organiser or your healthcare team.
- Social online forums are another great way to connect with others on the same journey. These can be particularly useful if you are in a regional or remote community. Again, HeartKids has a private Facebook group for young adults along with an Instagram page (see resources).

Learning goals

They should start to build and form relationships with others on the same journey as themselves. This will help them learn how to better manage their healthcare and wider life challenges. Seeing that others have succeeded with the same problems and challenges they have helps build self-efficacy and makes them more likely to try new things and to succeed at them!

Resources to help you teach

More information can be found on Teen Camps via this QR link.



HeartKids also provide social forums and the MyHeart social group is an official online community specifically for young people (13-25 year-old) with CoHD. You can find the group via this QR code link.



This is a link to the HeartKids Instagram Youth Zone.



Privacy concerns.

It is important to teach your teen about their rights around privacy in relation to healthcare. Research has shown that a fear of a lack of privacy is a barrier to young adults getting medical care and it is important for them to know what will be shared with you as a carer. Of course, as a carer, you would hope they would want to share everything with you but this is not realistic. Just as you might want to keep sensitive things private, so will they. If the healthcare practitioner thinks that it is the best interests of the patient they are obligated to share information, otherwise they will uphold the privacy of your young adult.

Teaching activities and pointers!

- Both you and your adolescent should read through the 2 resources provided on privacy. It is important you read them as this will help you to understand what legal and ethical considerations are made to protect your teen's privacy whilst keeping them safe.
- Have a discussion with your teen around privacy and try and answer any questions they have. If there are questions raised that you aren't sure about get them to write them down and discuss this with the healthcare team or GP next time they see them.
- Get your teen to describe what they think privacy in healthcare is to make sure they have understood the concept.
- It is important to give your adolescent time to meet with healthcare professionals alone so that they can talk privately around things that concern them.

Learning goals

Your teen should understand the implications of how their privacy will be maintained in their interactions and conversations with healthcare professionals.

Encourage your teen to speak openly with healthcare professionals and understand that their confidentiality will be respected.

Make sure they have opportunities to discuss their health without you present during healthcare visits.

Resources to help you teach

These are 2 resources with more information for you and your young adult around privacy



Let your teen talk to the cardiologist, GP and other health care workers alone.

This is a tough step for many parents and makes many feel uncomfortable. Remember that you will still be able to talk with doctors after the appointment and that this is an important step towards independence for your teen. It is important to get teenagers used to managing their own health by allowing them to practice before they are out on their own.

Teaching activities and pointers!

- Prior to them spending time alone with healthcare professionals make sure that you allow them to answer questions in consultations wherever possible to build their confidence.
- Remember to get them to prepare questions before they meet with the health care professionals.
- Make sure they have all of their information organised and at hand that they might need for the appointment the day before.
- The UpBeat app is great for organising the information that they might need at hand.
- Ask the healthcare professional about making sure that your teen has opportunities to meet with them independent of you.

Learning goals

Build confidence and skills in dealing with healthcare professionals and advocating for their own care.

They should learn to be responsible for posing and answering questions in appointments as well as collecting and documenting the outcomes.

Resources to help you teach

This resource has a section on how to talk to health professionals to help guide your teen.



LESSON 17

AGE 14+

If you have private health insurance explain how it works.

Private health cover is an important part of healthcare in Australia. If you have private health cover it is important that you explain how it works with your teen.

Teaching activities and pointers!

- Explain what the policy covers and where they can find relevant information such as the health insurers contact details and the insurance policy number.
- Get them to record this information in the UpBeat App.
- The Department of Health and Aged Care also has information on the use of health insurance in Australia which you can work through together.
- Get them to use their card for the private health insurance when you are utilising it at healthcare appointments i.e. the dentist.

LESSON 18

AGE 16+

Obtaining a driving license.

Driving a car offers independence, increases job opportunities and is an important part for many teens transition to young adulthood. For many people in regional and remote areas it is a key skill and can help them gain control of their lives and provide access to healthcare.

Teaching activities and pointers!

- Once your teen is old enough you can assist them to apply for a driving license and help them to start learning to drive.
- For some people with CoHD there may be driving restrictions, so it is important to discuss this with your cardiology team. Get your teen to ask the question when they next see the GP or cardiology healthcare team.
- If restrictions are in place having an open and honest conversation around this with your teen is vital in them gaining acceptance of limitations and finding alternate ways to travel and achieve independence.

Learning goals

They should be able to understand the role and importance of health insurance and that they may eventually need their own policy when they can afford one, and have the information needed to utilise when needed.

Resources to help you teach

The Department of Health and Aged Care also has information on the use of health insurance in Australia which you can work through together. This can be accessed via this QR code.



Learning goals

All eligible teens should, once they are of age, start the process of looking to acquire a driving license.

Understandably if there are economic barriers this may have to be put on hold.

It is important to look at the process even for those who may have restrictions placed on them because of their CoHD as this will give them insight into why the restrictions are in place and if, and when, they may be lifted.

Resources to help you teach

Look up your states road and traffic authority for further guidance on specifics around licensing.

Disability advocacy.

This may not be relevant to your teen. However, if they are currently receiving support or will need support in the future from the NDIS it is good to introduce them to the scheme and find out together what support it can provide.

Teaching activities and pointers!

- Read through the resources provided and visit the NDIS website together so that your teen starts to understand the role of the NDIS and the support it can provide.
- If questions are raised these can be discussed directly with the NDIS or you can get advice from your GP or healthcare team. Get your teen to write any questions down so they can ask them at their next healthcare visit.

Learning goals

Your teen should understand how the NDIS can support them and the process involved to access the support services they need.

Resources to help you teach

These are 2 resources that can help with this including a link to the NDIS website. The NDIS can also be contacted directly on 1800 800 110.



The importance of ongoing care.

It is important to discuss and make your teen aware of how important it is stay in care, how often they should get care, and the importance of getting specialised adult congenital heart disease (ACHD) care.

Teaching activities and pointers!

Cover the important points below:

- CoHD is a lifelong journey, but with appropriate adult care people can remain healthy.
- People who don't receive appropriate care can develop new problems or end up requiring emergency care.
- Even though they may feel well and not have any upcoming procedures or surgeries it is important to stress that ongoing care is required for people living with CoHD. Ongoing care helps to detect new emerging problems before they become serious.
- If not known already, make it a priority to find out their care plan as they move into adulthood from the healthcare team. Get them to write down the questions they need to ask to clarify things.
- Make sure that their transfer to adult care has been arranged and that they have met with the adult care team and are sure of the plan for their care moving forwards.

Learning goals

Your teen will have an adult care specialist in place, understand the future care plan for them and understand the importance of ongoing attendance of appointments for their health.

Resources to help you teach

Your cardiac care team should be able to help with any questions you have regarding ongoing care in to adulthood and this should be part of the transition plan for your teen.