



Transition and Transfer

Your move from Paediatric
to Adult health care services

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Transition and Transfer

Paediatric to Adult Health Care Services

If you are a young person being treated at a children's (paediatric) hospital, you will eventually need to be transferred to an adult kidney care service.

“ Your transition process should start as early as possible usually between 12-14 years. ”

This transition should be a gradual, individualised and planned process to ensure it works for you and your parents or carers, as the responsibility for your health and your health care team changes.

You are increasingly encouraged to manage your health care by yourself! During the transfer process, which usually occurs around 18 years of age, you will be encouraged to have more independence and do many more things for yourself, if you are not doing this already.

This does not mean you will lose support from others, just recognising that you are reaching an age where you can start to look after yourself more. It is also a recognition that legally you have certain rights and responsibilities as you become an adult such as the right to privacy.

Within this booklet there is information about this time in your life and how the transition and transfer process will occur including tips, references and links to further information and resources.



Your team

Providing support and assistance



Your move

Transition and transfer to adult health care



Your health

Maintaining a healthy and active lifestyle



Your future

Providing support and assistance



Your resources

Financial and other support systems

Your health care team



Living with kidney disease, as a young person will usually mean that your kidney care team (nephrology) is located within a paediatric hospital.

The level of care provided by this team usually depends on your level of kidney function and how much follow up and/or treatment you require. You may also have community supports as part of your health care team. You should have a regular General Practitioner (GP) who knows you and who you trust to assist with your medical care.

Many health aspects can (and should) be managed by your GP and not your kidney care team. During the transition process, it is important to find a GP to work with you and your health care teams to keep you as well as possible.

It is important to remember that YOU are the most important person in your health care team. During the transition process, other members of your health care team will help you to become as independent as possible before you transfer to an adult health care service.

Health professionals and others who may be a part of your health care team are shown in the diagram below:



Your broader support team



Carers/Parents role and transition to self-management

Your parents or carers usually play a major role in looking after you. You may have depended on them to be there to understand the information being given by your health care team and to make most of the decisions for you.

As you get older, you will need to know more about your kidney condition and learn how to manage your health care. During the transition and transfer phase the role of your parents or those who have helped care for you over time may gradually change. As you become more comfortable with and are able to manage your own health care needs, you may be able to get by with less support. This doesn't mean that they are removed from your support team rather that they may take on a different role.

Friends & Partners

Your friends or partners can be an important part of your health care team.

Telling them about your health can help them to understand the changes and challenges you are going through and can help you to stay positive and confident too.

You may also like them to attend your appointments with you especially as you become an adult and become more responsible for your health care.

Peer support

Connecting with other young people living with kidney disease or a similar condition can be a great support to share information, experiences and develop valuable friendships.

In some cases, this peer support and social connections might be provided by the hospital through attending a transition or young adult clinic. Special activities, events or social media forums are also coordinated by organisations like Kidney Health Australia and Livewire to provide opportunities to meet other young people.

If you would like to be connected to peer support opportunities, you can discuss this with your health care team or contact Kidney Health Australia (See the Youth Support Service section of this brochure)



“

You can talk to people so much about what's going on, but unless you're living it no-one really understands the struggles you face.

”

Getting the most out of your health care



Do you know why you have chronic kidney disease (CKD)?

Do you know the stages of CKD, what stage CKD you have and what that means for you now and in the future?



Learning about your kidney condition will help you understand why you need medical check-ups and why you may need lifestyle adjustments (diet, fluid targets/restrictions) or treatment (medications, dialysis, transplant).

Medical and allied health appointments are important so that your health care team can monitor your kidney function and overall health and create a follow-up and treatment plan. Your health care team should explain each part of the plan and why it is required. This will help you make decisions around your health, healthcare and treatment options.

Your health care team will encourage you to have appointments (or part of an appointment) on your own so that you can learn how to take charge of your health and health care plan. You can still have a family member or friend there if that's what you want but the discussion will be directed to you. Don't be afraid to ask lots of questions which will be helpful for your health, your lifestyle and your future.

Before the visit



- Make a list of questions you need answered (This may include symptoms, concerns or changes in your life that may have occurred since your last visit).
- Learn the name and dosage of medications you are taking. Try keeping a list that you can bring to your appointment (e.g. in your phone).
- Check your prescriptions to see if you need new ones and make a note to ask for them.

During the visit



- Ask your questions and write down the answers. Most people remember only about half of the information given to them.
- Before leaving, make sure you have a clear idea of your treatment plan. If you do not understand something ask your health care team to explain it in other ways which you can understand.
- If there are several medications to take or other complicated treatments to follow, ask your health care team to write them down for you.

After the visit



- Make a list of recommendations given to you and try to follow the advice.
- Don't be afraid to contact your health care team between visits with any concerns.
- Trust and respect is important in any relationship. If you do not feel comfortable with any member of your health care team, it may be worthwhile seeking a second opinion. Different people are suited to different styles so find someone you can relate to.

Your move



Transfer to adult health care usually occurs after you have completed high school or left school to start work (usually between 17 to 19 years of age).

Some young people transfer earlier or a bit later depending on where they live, whether their health is stable or if they have many health needs. Your feeling of readiness to transfer may be different to others but you will hopefully have been preparing for this move for some time. Your medical and emotional stability at this time is also important to consider so this can be as smooth a process as possible. Discussions with your health care and support team will determine the best timing for this.

Don't be afraid to ask lots of questions and talk to someone about your concerns. This is all part of the transition process.

As a young person with a kidney condition you may get a choice in where and who your adult kidney care team will be. This is due to your stage of chronic kidney disease, the level of medical care you need and where you live/study/work. This may also vary from state to state and your paediatric nephrology team will discuss this with you as part of the transition process.

Do I have to go to my appointments by myself?

Will my new adult health care team know me?

How do I say goodbye to my current health care team?

Will I like my new adult health care team and service?

What about my future? Will I be okay?

Do I have to learn all these tasks? Can't someone else do it?

Will the adult health care team/environment be the same or different?

Will my adult health care team have my health information?

I don't want to be a young person with a health condition! Can't I just be like my mates?



Preparing for your move



Your health care team and/or transition team will work with you to help you set goals, develop skills and knowledge with:

- Your medical condition
- Scheduling and attending appointments
- Reaching your goals with school, further studies or employment
- Your treatment and emergency plans
- Obtaining scripts and filling prescriptions
- Coping with challenges
- Preparing for the adult healthcare service and knowing who they are
- Maintaining a healthy and active lifestyle
- Finding resources and support services.

Some common questions you may have about your transition



What gaps are there in my knowledge and health care skills?



What are my transition goals?



How do I improve my knowledge and health care skills?



What support and resources do I need and how do I find them?



Do I have an individual Transition and Transfer Plan?

The main objective in transition is to assist you towards independently managing your health care and preparing you for the future.

Some common questions you may have about the transfer process



What is the transfer process and how will it work for me?



How will the adult health care service know about my medical history?



Do I have a say in where I am transferred to?



Will I get to meet the adult health care team before I transfer?



How will I know I am ready to be transferred?

The main objective in transfer is to ensure there is no disruption to your medical care and support!

Your health



A healthy lifestyle is important for everyone and especially if you have a kidney condition. A healthy lifestyle includes learning to make choices that will help you have the best physical health and mental health now and in the future.

Medication essentials

Managing your medication is an important part of treatment for kidney disease. Each medication is given for a reason and should be taken as directed. It is important that you do not stop taking any medications without checking with your health care team first.

Take your medications regularly as directed and get into a good routine. Strategies and tools can be helpful in reminding you to take your medications (using alarms or apps on your phone, dosette boxes or Webster packs, putting your medications in a handy visible spot such as next to your toothbrush). It's important to use whatever works best for you!

It is also important to be aware that some medications may interact with medication you take. This may be prescribed medications (e.g. antibiotics) or over the counter medications or health supplements such as herbal products. You should always check with your pharmacist or nephrologist whether it is safe to do so before starting.

Other substances - Drugs

Drugs can be legal (e.g. cigarettes, alcohol, prescription and over the counter medications, cannabis – in some states) or illegal (e.g. GHB, MDMA, ICE, cannabis – in some states). Illegal drugs incur criminal charges and should be avoided.

Any drug can have risks and be bad for you. Having a kidney condition can increase your risks and it is important that you know the risks before making choices.

Legal drugs

Smoking (cigarettes and vaping) is unhealthy for you and should be avoided. It causes many health issues (e.g. lung disease, heart disease and vascular, cancer).

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Alcohol (Illegal under the age of 18)

Many people enjoy alcohol, but it is important to know that there are risks and it should be consumed responsibly.

You should talk to your health care team about whether there are safe limits/options for you. The advice may change with different levels of kidney function or medications that you may be taking, and you may decide that it is best not to drink alcohol at all.

Alcohol affects how your kidneys filter waste and water. If you have chronic kidney disease your kidneys may not be able to do this as effectively.

Short term effects of alcohol

- Passing more urine than usual: can cause dehydration which can cause kidney injury.
- Vomiting: from stomach irritation or alcohol poisoning.
- Changes in blood pressure (high or low).
- Altered brain function: can make you sleepy, unable to concentrate, forgetful, mood changes, changes how you make decisions.
- Medication interaction: changes absorption, blood levels, side effects.



How can I drink safely?

- Ask your doctor if it's okay for you to drink alcohol and how many standard drinks they would recommend.
- Check with your pharmacist or doctor about medication interactions.
- Always drink lots of water (if no fluid restriction).
- Don't get drunk, it might make you vomit, get dehydrated or be unable (or forget) to take your essential medications.
- If you take essential medications (especially immunosuppressant's) make a plan so that you don't miss taking them.





Exercise and sport

Being physically active every day has many positive effects on your health and wellbeing.

Whatever your stage of kidney disease there are lots of reasons to exercise regularly, including:



As kidney disease progresses, maintaining or improving your fitness may be difficult but it is still very important. Do as much as is comfortable and think of it as part of your treatment.

Some contact sports may need to be avoided, particularly while on dialysis or after a kidney transplant.

If you have a dialysis catheter, you need to protect it while exercising (by using extra dressings. If you have a kidney transplant you may decide to use a specially fitted transplant kidney guard. It is best to discuss this with your dialysis or transplant nurse or nephrologist.



Diet and Nutrition

What we eat and drink is important for our current and long-term health.

If you have good kidney function you will not need to restrict your diet but should aim to follow general healthy eating guidelines. Low sugar and low-fat foods and drinks are best!

If your kidney function is declining or if you are on dialysis, you may need to restrict or stop eating and drinking certain foods and drink. This will be discussed with you by your nephrologist and renal dietitian. This is to protect your bones, blood vessels and remaining kidney function.

If you have had a kidney transplant the medications can make you feel hungry. If you eat a lot of food or drink that has a large amount of fat or sugar in it, it can cause you to put on a lot of weight very quickly which can be hard to lose. This can cause other problems like diabetes and heart disease as you get older. You should try to drink lots of water and avoid fast food as much as possible.

More information about living with kidney disease and managing your health and wellbeing can be found on the Kidney Health Australia website:

kidney.org.au/your-kidneys/living-with-kidney-disease/health-and-wellbeing





Depression, anxiety and stress

Adolescence can be a roller-coaster ride which can be complicated, delayed or affected by your health and wellbeing. Having a kidney condition may be extra challenging at times and can feel overwhelming.

How do I feel?

Is it normal to feel this way?



You may feel:

- Like you have low mood or depression. It can be hard to get out of bed or be motivated to do anything. You may feel a little bit or very sad.
- Anxious or stressed. Hard to sit still or concentrate. Feeling nervous or worried.
- Forgetful, cannot remember information or tasks.
- Confused or not able to understand simple things.
- Irritable, edgy, moody, angry, frustrated.
- Tired most of the time, low energy levels, not sleeping well.

Some of these feelings/symptoms may also be related to the physical changes caused by your kidney function decreasing (due to the build-up of waste products in your blood) or caused by the medications you are taking.

If you are experiencing low mood, anxiety or stress, it is best to talk to someone about how you're feeling. You can ask for advice from your nephrologist who can explore possible medication side-effects or your GP who can link you in with psychology support through a Better Access Initiative to Mental Health Care Plan. You may also be able to get support from a renal social worker or psychologist.

There are online resources that can help you work through your feelings. If you need some help but are unable to get it straight away or don't want to speak to anyone directly this may be a good option or starting point for you.

Check out the Youth Support Services section of this booklet for some links.



Your sexual health and safety is also an important consideration at this stage.

Sexual health

Adolescence is a time when you may be having sex or thinking about it. The most important thing is that it is healthy and safe and that you should wait until you are ready.

Having kidney disease can affect sex, fertility and pregnancy. Your health care team should discuss sexual health and safe practices with you.

It might be a bit embarrassing (especially the first time) but think of it as another part of your health journey that is as important as anything else.

Discussing this early on can be helpful in understanding how future parenthood may fit into your life, your situation and how it may impact on pregnancy.

Information about Sexuality, Fertility, Contraception and Kidney Disease can be found in the Kidney Health Australia fact sheet: kidney.org.au/resources/factsheets-and-photosheets/sexuality-fertility-and-kidney-disease-factsheet

Contraception

Contraception is very important to prevent sexually transmitted infections (STI's) and pregnancy.

You should decide what type of contraception you would prefer (and start) before you start having sex. Contraceptive agents such as the pill, Mirena, IUD will help prevent pregnancy and condoms will help prevent STI's and pregnancy.

You can discuss contraception with your community supports (GP, school nurse, sexual health nurse) or Nephrology team. There are also online resources and fact sheets that you may find helpful (headspace, family planning site in your state).

Sexual health and immunosuppressant medications

Fertility and pregnancy



- Some medications that suppress the immune system or treat viruses can seriously affect a pregnancy.
- It is important that any young person or adult who is on these medications is using contraception (including condoms).
- Your health care team and pharmacist will give you further information about this.

Infections



- STI's can be more common or harder to treat in people taking immunosuppressants.
- STI's can cause minor or serious health issues such as discomfort, rash, sores, infertility and cancer.
- It is very important to prevent them by using barrier protection (condoms).

Your future



Driving

Everyone needs to be medically fit to drive a vehicle.

For people living with kidney disease restrictions are usually minimal and this can be discussed with your doctor.



School

During transition, you may also be finishing school and/or thinking about what's next, including exploring alternative pathways.

Your school or health care/transition teams can be a great source of support. They can help you to access special provisions for exams, negotiate school supports, navigate special consideration for entry to university or TAFE including scholarships and assist with career planning and other workplace supports.



Work

Telling your employer about your health condition can lead to better understanding and access to extra support at work if you are unwell.

Remember that your employer is responsible for providing a safe and inclusive work environment for you.

You may also be required to provide a 'Fit to Work' letter from your doctor which outlines your health condition or provides a medical opinion that says you are fit to work.



Travel

Travel both domestically and internationally is possible but does usually involve special preparation which can be discussed with your health care team.

This could include:

- Arranging dialysis.
- Ensuring communication with your health care team whilst you are away.
- Special considerations regarding transporting medication, equipment and essential extras.
- An up to date health condition letter from your doctor.
- Making sure you have extra medication supply.
- Emergency planning (in case you get sick or injured, lose your meds etc.).



You should always arrange travel insurance before booking overseas travel.

Further information and tips on managing money, work and travel can be found on the Kidney Health Australia website:

kidney.org.au/your-kidneys/living-with-kidney-disease/managing-money-work-and-travel

Your resources



Government Systems (health care and financial support)

Creating a My Gov Account

A My Gov account enables you to access a range of government services online such as Centrelink and Medicare, The National Disability Insurance Scheme and My Health Record.

The process is simple and the My Gov website is the starting point for registering. my.gov.au/LoginServices/main/login?execution=e1s1

Medicare

Medicare is the publicly funded health care system in Australia (for citizens and those eligible) which helps with the cost of medical health care. Legally you can obtain your own card when you reach 15 years of age and should have one to access medical services independently.

The application form can be found and downloaded at: www.servicesaustralia.gov.au/individuals/forms/ms011

You can lodge your form at a Medicare service centre, and you will need to bring one of the following:

- Driver's license
- Current passport
- Birth certificate

When you are going for a check-up or treatment always take your Medicare card with you.

Medicare covers the cost of:

- All public hospital clinics
- Treatment as a public patient in a public hospital
- All or part of the costs of treatment by practitioners such as Doctors (including specialists).

Chronic disease management plan

Accessed via your GP for a limited amount of allied health services (physiotherapy, dietician etc.).

Dental care

- Child Dental Benefits Schedule (CDBS): Until the age of 17 you may be eligible if you or your parent or partner is also receiving a Centrelink benefit.
- Public dental care services: check your state department of health website for eligibility criteria.

Medicare Safety Net

The Medicare Safety Net scheme ensures that when you spend certain amounts in gap and out of pocket costs, you'll reach the threshold (then you'll get more money back for certain Medicare services).

Medicare Bulk Billing

Your doctor accepts the Medicare benefit as full payment and bills Medicare directly rather than expecting you as the patient to pay up front.

To find out more about [Medicare](#) and the charging of fees, how to apply for your own card and more visit the [Services Australia Website](#) or phone 132 011 for general enquiries.

Private Medical Insurance

If you have private family health cover, you may be eligible to continue to receive cover until you reach the age of 25 depending on the terms and conditions of this cover. Otherwise, you may need to consider a singles cover for yourself.

Some private health insurance policies cover chronic kidney disease, including dialysis. You can check what's available at [Compare the Market](#) or visit www.privatehealth.gov.au

Centrelink

If eligible you can apply to obtain a Healthcare Card. This entitles you to reduced costs for medicines as well as other concessions. When you turn 16, you will need to re-apply for your health care card.

[Centrelink](#) online will help you find out if you are eligible. Centrelink offices can be busy with queues and you may have a long wait with telephone enquiries.

Alongside your Health care card, you can also discuss assistance with further education, work and any other entitlements assistance such as paying your bills and accessing cheaper public transport.

Disability support

Disability Support Pension

The Disability Support Pension provides financial assistance to individuals with a permanent physical condition. You will need to be assessed by Centrelink to find out if you are eligible.

National Disability Insurance Scheme (NDIS) accessibility

The NDIS provides individuals with permanent and significant disability with funding to access services and supports that will enhance their quality of life including carer support.

www.ndis.gov.au

Dialysis

Dialysis financial assistance (for use of water, electricity)

Concessions are available for those on dialysis in the home. These conditions vary by state and territory.

For more information you can access the Kidney Health Australia website. kidney.org.au/uploads/resources/financial-and-general-support-for-dialysis.pdf



Medications

Pharmaceutical Benefit Scheme (PBS)

The PBS ensures that medicines for most conditions are subsidised by the government.

Health care card concession

If you have a health care card you may be eligible for low cost medications.

Travel (for rural and interstate patients)

Assisted Travel Schemes are available Australia wide. These schemes provide financial assistance to eligible patients to access specialist services that are not available locally.

Carers

Carer Support

Is available Australia-wide. Carer support in your state might include financial support, respite and discounted travel.

kidney.org.au/your-kidneys/living-with-kidney-disease/families-and-carers

Kidney Health Australia

www.kidney.org.au

- Health information
- Fact sheets
- Support groups
- Advocacy
- Events
- Fundraising
- Research

Kidney Helpline

Phone 1800 454 363 or
email Kidney.Helpline@kidney.org.au

'My Kidneys My Health' app

The 'My Kidneys My Health' app focuses on helping you to understand your kidney disease. It also provides information about how you can take control - you can make lifestyle changes to slow down any future kidney damage. This app also lists many useful contacts and supports that can help you through your journey with kidney disease.

To download visit the [Apple App Store](#) or the [Google Play Store](#).

Want to know more about kidney transplants?

Kidney Transplant Xplained provides important information in an easy to understand illustrated story.

Download now for free

Available on the App Store

Get it on Google Play

Kidney Transplant Xplained app

Kidney Transplant Xplained is a free app that helps explain the kidney transplant through storytelling. It is based on the experiences of two real patients and breaks down what kidney transplants involve, from pre-transplant preparations to life post-transplant. It also includes medication logs, appointment management, the ability to choose a support person, and more.

Kidney Health Australia worked with Medicine X on this resource, designed for patients who are considering, about to get, or have recently had a kidney transplant. Kidney Transplant Xplained is available online for free via the [iOS App Store](#) or [Google Play](#).

Youth support services



Mental Health and Wellbeing Support Services

Headspace

Headspace Centres act as a one-stop-shop for young people (12 – 25) who need help with mental health, physical health (including sexual health), alcohol and other drugs or work and study support.

headspace.org.au

SANE

1800 18 SANE (7263) 9-5 weekdays for information and advice

Translation/Interpreting Services

131 450

Parents and Carers Support Services

Carer's Australia

1800 242 636 carer's advisory and counselling service.

Parents and Carers Facebook Group

For parents and carers with children living with kidney disease.

Crisis Support Services

Beyond Blue Youth

1300 222 4636 (24 hrs) telephone and online support.

Kids Helpline

1800 55 1800 kids and youth (5 to 25) and parents.

Lifeline

131 114 (24 hrs) crisis telephone counselling.

Suicide Call Back Service

1300 659 467 (24 hrs) free crisis telephone support.

Social Networking

Kidney Youth Australia Facebook Group

For youth (15 to 24) living with kidney disease.

Livewire

Online moderated chat for young people (10 to 20) living with a serious illness, chronic health condition or disability, and siblings.

CHiPS - Social and peer support

For youth (12 to 25) living with chronic illness.

Royal Children's Hospital Melbourne & Sydney Children's Hospital's Network: ask your team about a referral to this program. Other states check with your hospital whether there are similar local programs.

Clinical Support Services (transition services)

The Royal Children's Hospital Melbourne

- Transition Support Service – includes information on the service, fact sheets and resources.

Agency for Clinical Innovation Sydney

- Transition Care Resources.
- Trapeze dedicated to helping young people transition into adult care.

Kidney Helpline

Phone 1800 454 363 or email Kidney.Helpline@kidney.org.au



Am I ready for transfer?



Knowing about my kidney condition and treatments

Being independent with my health care

Keeping well

Planning for transfer

Can I confidently describe my kidney condition and other health concerns?

Do I know about my treatments and medications, including dosages and side effects?

Do I know the effect of smoking, alcohol and illicit drugs on my kidney health?

Do I know how/if my kidney condition impacts on my sexual and reproductive health?

Do I know which tests I have regularly and why I need them?

Am I responsible for remembering and taking my medications/treatments?

Am I responsible for accessing scripts and having them filled?

Do I know who to contact if I have any questions about my kidney health and how to get in touch with them?

Can I make my own appointments?

Do I know who to contact if I need help with my appointments?

Have I had time alone with my healthcare teams?

Am I comfortable asking my healthcare team questions and advocating for myself?

Am I aware of my healthcare rights and responsibilities?

Do I know the symptoms to look out for if I am feeling unwell?

Do I know what to do if I become unwell or need urgent medical care at all hours?

Do I have strategies and supports in place if I am feeling stressed or upset?

Do I know where to access information to support my educational/vocational future, peer support and general wellbeing?

Do I have a transition plan which I have discussed and contributed to with my renal and transition teams?

Have I provided my correct contact details to my nephrologist to include in my referral letter?

Do I have copies of my hospital letters and referrals?

Do I have the contact details of my new adult healthcare team?

Do I know how to get to my new adult hospital/service?

Do I have a regular and trusted GP?



Kidney Health Australia

Visit: kidney.org.au

Call: 1800 454 363

Email: Kidney.Helpline@kidney.org.au

 **Kidney Health**
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