



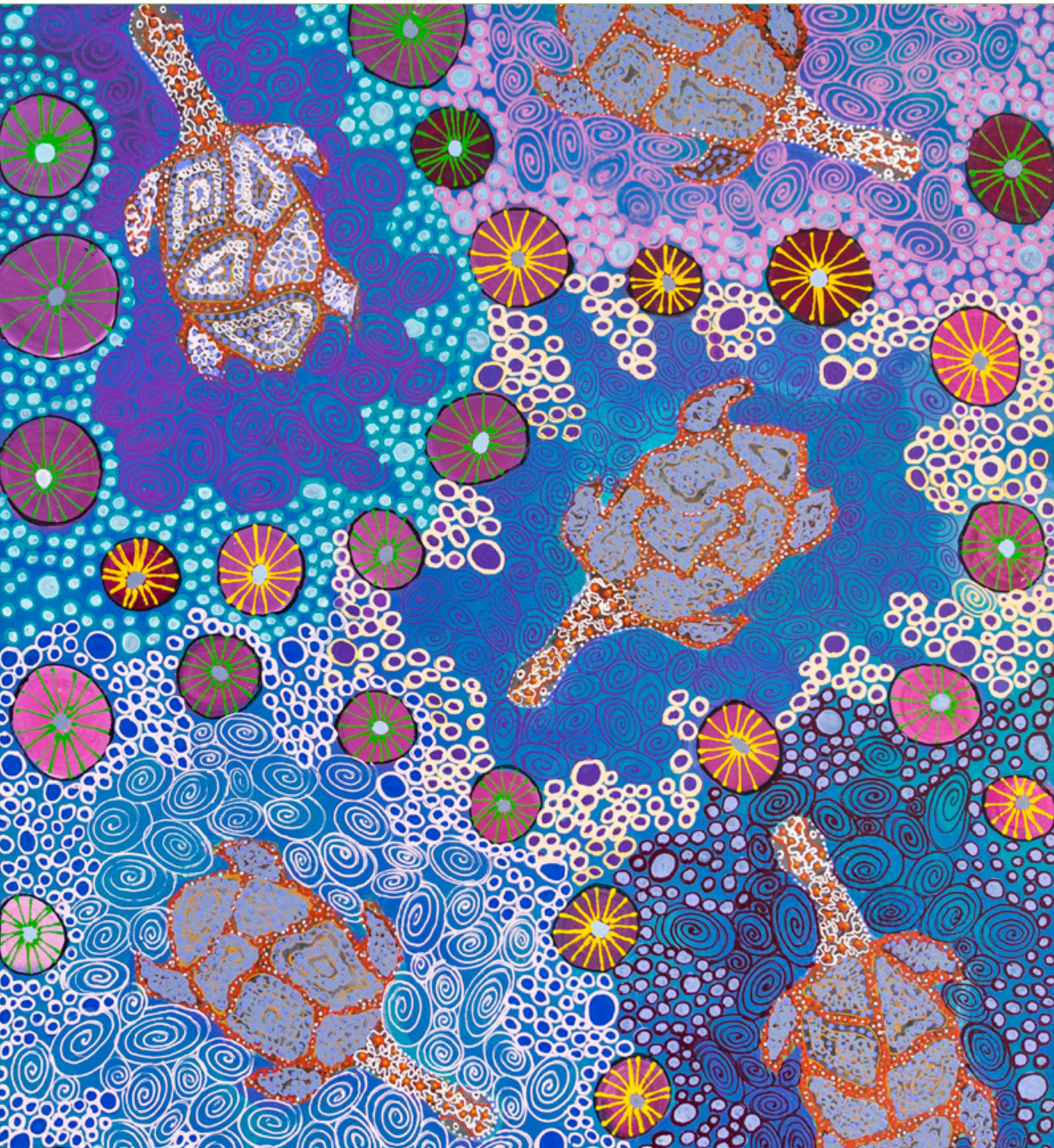
# Managing your care

A guide to help young people transition  
from Queensland Children's Hospital to  
adult kidney care



Queensland  
Government





**Artwork pictured above:** Rhindi Season 2020 | Acrylic on canvas

**Artist:** Sandra Ase | **Language group:** Teapathiggi

Sandra Ase is an emerging Aboriginal and Torres Strait Islander artist who works in Mapoon in West Cape York. Her artwork depicts her country, which she describes as “my provider and sanctuary”. This painting shows sea turtles in the bright summer waters as they prepare to hatch.



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## Acknowledgements

Children’s Health Queensland pays respect to the traditional custodians of the lands on which we walk, work, talk and live. We also acknowledge and pay our respect to Aboriginal and Torres Strait Islander Elders past, present and future.

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## Interpreter services

The Queensland Government is committed to providing accessible services to Queenslanders from all culturally and linguistically diverse backgrounds. If you have difficulty understanding this guide, you can contact us on 07 3068 3365 and we will arrange an interpreter to effectively communicate the guide to you.

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## Why is this guide important for you?

We understand that even the thought of ‘transition’ can be scary, but we want you to know that Queensland Children’s Hospital is still here to care for you. This guide is just to help you understand the transition process and let you know how we will help you to be ready when you’re eventually old enough to transfer to an adult health service.

*This resource is provided through the assistance of funding from Advancing Kidney Care 2026, Clinical Excellence Queensland, and the support of the Statewide Clinical Renal Network.*

# Who is this guide for and what is it about?

If you are a young person aged 12 years and over, being cared for by the Queensland Children’s Hospital (QCH) kidney team, this guide is for you and your family! It aims to help you manage your health care, alongside the rest of life, while preparing you for your ‘transition’ from the QCH kidney team to adult kidney care services.

This guide will talk about the common challenges young people face as they head towards transition. It will help you understand what transition is, how to support your health during transition, how adult services work and how to access adult services. For more general information about transitioning to adult services, click this link to access [Transition to adulthood – A guide for adolescents and young adults](#). Here you will find lots of helpful information, resources and tips to help you with common changes that happen as you get older.

## What is ‘transition’? Why is adult kidney care different?

As we get older, there are lots of transitions that we face in life. This includes with school, study and work, new relationships, our sense of self and understanding our direction in life. However, when we talk about transition in this guide, we mean the process of taking control of, and self-managing your health and care, while also managing the move from the QCH kidney team to adult services. You might already be managing lots of your own care, or you might not. Everyone is different and either way, this resource will help provide you with strategies to manage your health alongside your life.

As you move to become an adult, you will transition to a new nephrologist (kidney doctor) that specialises in adult care. Their specialist input is important to continue supporting your kidney health as you get older. To prepare for this, between the ages of 12 - 18 your healthcare team at QCH will work with you and your family to help you build the skills you need to manage your health care. They can also help you to understand how adult services work. They will help by showing you the steps in your plan for transition, the things you need to practice and the people to contact for advice.

## Important medical terms

<b>Adolescent</b>	A young person in the process of developing from a child to an adult.
<b>Consultant</b>	A senior specialist who trains other doctors to treat patients in their specialty field.
<b>Dialysis</b>	A medical treatment to help clean your blood when your kidneys slow down.
<b>GP (General Practitioner)</b>	A GP is a local doctor who helps to support your general health in the community and communicate with your specialist doctors.
<b>Immunosuppressant</b>	A medication that slows down your immune system. This can be used to help your body accept new organs after having a transplant surgery.
<b>Indigenous liaison officer</b>	Staff that provide cultural support and advice to Aboriginal and Torres Strait Islander patients and their families.
<b>Kidney care</b>	Actions to help your kidney health.
<b>Nephrologist</b>	A specialist doctor focused on kidney health.
<b>Paediatric</b>	A type of medical specialty relating to children and young people.
<b>Paediatrician</b>	Specialist doctor who helps children, until 16-18 years old.
<b>Registrar</b>	A senior doctor who supervises residents and medical students.
<b>Renal</b>	Related to your kidneys.
<b>Resident</b>	A doctor who is in training to specialise in a particular field of medicine.
<b>Transition of care</b>	Transfer of care from a paediatric health service to an adult health service.
<b>Young adult</b>	A person in the early stages of adulthood.

## Common challenges for young people and families

Many young people and families tell us that transition can be scary and hard to manage because of the thought of moving away from your health care team to something unfamiliar. Young people also tell us that managing their health, alongside life's other priorities can be a challenge.

### Some common challenges young people experience include:

- Managing health alongside competing work, study, and social commitments.
- Feelings of low mood or mental health struggles.
- Low motivation to take medication and engage in health care.
- Not knowing:
  - how to manage health and care
  - why medications are needed or prescribed
  - which medications to take, when or how much to take
  - how to make or change appointments, or get a new prescription
  - how to access a general practitioner or who to ask questions about your health
- Not feeling confident to ask questions.
- Feeling embarrassed talking with health professionals.
- Not having enough money for medications.
- Not being able to get appointments.

It is important to know that these struggles are common for young people, but that your healthcare team is here to help. We have been asked all these questions before, so it is important to let us know how you are feeling so we can help.

If you're struggling with your transition of care or mental health, you can read what supports are available to you in [Transitioning to adulthood – a guide for adolescents and young adults](#), let your QCH kidney team know, as well as your GP.

## The impacts of common challenges

As you become a young adult there are lots of new activities and responsibilities in your life that may become a priority for you. Sometimes this might mean that managing your care, attending appointments or taking medications is hard. This is a challenge as it can have a big impact on your health and the rest of your life.

If you've had a kidney transplant and find yourself struggling to stick with your medications or appointments, it's important to know the impact this can have on you. For example, some medications are needed so your kidneys continue to work properly and so your body doesn't reject your new kidney. If this happens, this can mean your kidney function rapidly slows down and you may require dialysis much sooner.

If you're having dialysis and you miss or skip treatments, your kidneys can't clean your blood properly. This will often mean you feel weak and tired and increases your risk of infection and being hospitalised.

We know that learning to juggle responsibilities is hard. That's why we aim to prepare you to manage your health and life as best as you can, as well as to make your transition to adult services easier. This is so important for your long-term kidney health and the rest of life.



# What is 'good' transition and the transition process?

There are lots of different steps in the transition process. This section helps you understand what the QCH kidney team is doing to help make it easier for you, and some things that you can do to build your confidence for transition.

## Individualised transition – tailored to you

Each person has different healthcare and lifestyle needs, which means that their transition into adult kidney care needs to be unique to best fit their situation. This unique transition means that it is very important to discuss and plan this process with your QCH kidney team. This helps make sure you have a smooth transition and can maintain your health. Topics for discussion may include: your current kidney function, medications, location of appropriate adult services, GP support and communication among other things.

Every young person has a different social and medical history, which means that you will have your own treatment and follow up plan. Your current and future stage of kidney function will likely impact and change the amount of treatment and follow ups you need in the adult service.

## Gradual transition – starting early

The transition process should start at around 12-14 years old. The transition process starts at a young age so that you have several years to build your confidence, knowledge, skills, and independence in managing your health and wellbeing. This also gives your QCH kidney team lots of opportunities to identify, refer and work together with your new adult health service to provide an in-depth and smooth handover process. Your carers and support workers will be involved throughout this process.

The aim is to support you to build your confidence and independence in managing your own health more each year before you transition to an adult health service. Your QCH kidney team can help you do this by practicing new tasks including booking new appointments, changing appointments and attending appointments by yourself more often as you get older.

## Planned transition – smoothing out the process

Your transition is a process with various steps to help you understand what to expect when you eventually transfer to an adult health service. Transition happens when you are between 16-18 years old. The time you transition will depend on your health and personal situation.

An important consideration in your transition process is talking with your QCH kidney doctor which adult service is best suited to you depending on your condition, location and other factors. You can see some of the different options on page 11.

Depending on your kidney condition and health, you will either be transferred to an adult kidney doctor or your GP for ongoing care. Before you leave and transfer from QCH, you need to know who you are being referred to. If you live in a rural or remote area, your GP will be a key person to help manage your health through transition. The QCH kidney team will start to work with and support your GP before you are referred to an adult service.

After you turn 16 your QCH kidney doctor will refer you to an adult service. Your QCH team will aim to organise several consultations with both you and your new adult service in the 1-2 years before you transfer. This shared consult might be in person or via telehealth, depending what is better for you and the adult service. Getting to meet your new adult kidney doctor before transfer helps you to build a relationship with your new adult healthcare team. It also helps your QCH team, GP and new adult doctors to handover all the important information they need.

“The aim is to support you to build your confidence and independence in managing your own health.”



## Transition of care journey – at a glance

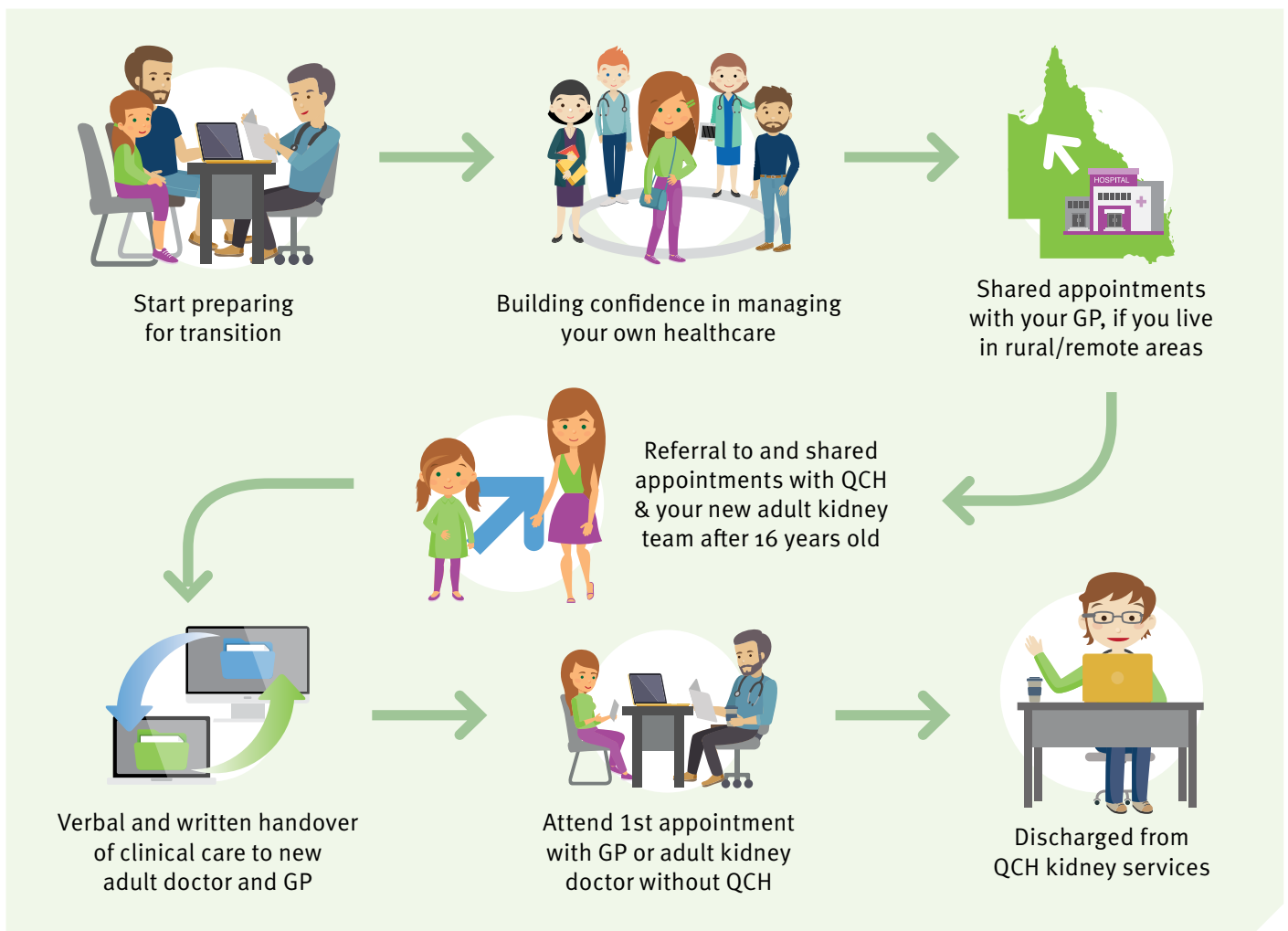
When your QCH and adult team or GP are ready, you will have your first appointment with your new kidney service. This appointment will only be with your new team, and the QCH team won't be in the appointment. After this first appointment at your new service, you will have one final appointment with your team at QCH.

This planned and gradual transition helps to make sure that your follow up in your new service doesn't get delayed or missed. It also means you're able to organise and complete any important tests and medical reviews for your new team, even if they're not required very often.

Your QCH team will provide your new adult service with your direct contact details. After you turn 16 years old and have

transitioned into your new adult service, you (instead of your parents) will be the main contact person. This is due to patient confidentiality and means that it is really important that you keep your details up to date. Your new service will then contact you to organise your new appointments.

When it's time for you to move from QCH to your new adult health service, your QCH kidney doctor will send a final detailed letter to your new kidney doctor and team. Your GP will get one as well, even if you don't see them often. You might also want to request a copy of your relevant medical information from the QCH kidney care team or transition support service for your own records.



# Patient journey examples

Every person's journey is different in several ways, but these are some example patient journeys that may have some similarities to yours.

## Patient journey 1

### Post-transplant patient that lives locally in Brisbane

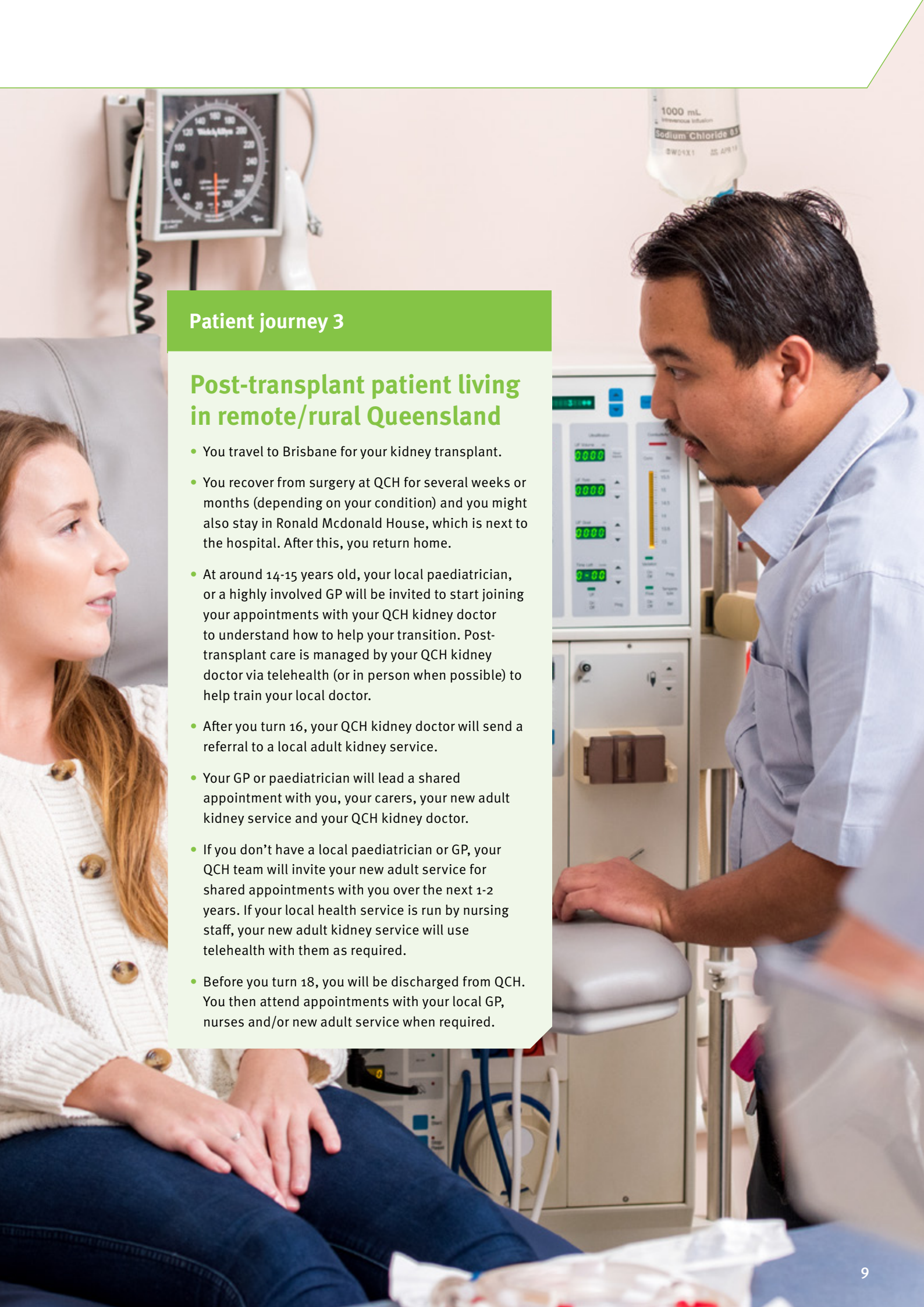
- After you turn 16, you will be referred to Mater Young Adult Centre (MYAC) by your QCH kidney doctor. MYAC is currently only available for kidney transplant patients, not for dialysis patients.
- Go to MYAC clinic for your first appointment with your parents or carers, along with other young people. You get to meet the adult kidney team, including your adult kidney doctor, occupational therapist and clinical nurse consultant (CNC). This is held in the morning tea hub. If you feel nervous, you can ask your QCH transition coordinator to visit with you.
- After you meet the whole team, there is time to hang out with other young people that visit the kidney clinic. Later in the day, you will have a 1 on 1 appointment with an adult kidney doctor.
- When you meet your new doctor, they will have very open conversations with you about juggling your kidney health and new things you might be exposed to while growing up (sex, drinking and drug use). It's up to you if you want to have your parents or carers with you for this part.
- After this first MYAC visit, you will still see the QCH kidney team. Before you turn 18, or earlier if you're ready, you will be discharged from the QCH kidney team.
- When you turn 25, or earlier if you want, the MYAC team will refer you to a local adult kidney service.

## Patient journey 2

### Peritoneal dialysis (PD)/ Haemodialysis (HD) patient that lives locally in Brisbane

- After you turn 16, you will be referred to your local hospital (e.g. Princess Alexandra Hospital). This will happen as early as possible, and your QCH Kidney team will try to organise several shared appointments with your new adult kidney service in the 1-2 years before you transition and leave QCH.
- Your QCH Kidney transition coordinator talks to your new local PD/HD nurses to identify if you will need training for new dialysis equipment. If you do, your new adult nurses will get in touch with you to train you with the different dialysis machine (most adult services use Baxter machines).
- After your QCH and new adult doctors are ready, you will have your first appointment with your new adult service without the QCH team. It could be in person at your new kidney service, or if you see nurses in the community they could call you and your PD/HD nurses via telehealth.
- After this first appointment with your new adult service, you will have one last appointment with the QCH renal team and then be discharged from the QCH kidney service.





### Patient journey 3

#### Post-transplant patient living in remote/rural Queensland

- You travel to Brisbane for your kidney transplant.
- You recover from surgery at QCH for several weeks or months (depending on your condition) and you might also stay in Ronald McDonald House, which is next to the hospital. After this, you return home.
- At around 14-15 years old, your local paediatrician, or a highly involved GP will be invited to start joining your appointments with your QCH kidney doctor to understand how to help your transition. Post-transplant care is managed by your QCH kidney doctor via telehealth (or in person when possible) to help train your local doctor.
- After you turn 16, your QCH kidney doctor will send a referral to a local adult kidney service.
- Your GP or paediatrician will lead a shared appointment with you, your carers, your new adult kidney service and your QCH kidney doctor.
- If you don't have a local paediatrician or GP, your QCH team will invite your new adult service for shared appointments with you over the next 1-2 years. If your local health service is run by nursing staff, your new adult kidney service will use telehealth with them as required.
- Before you turn 18, you will be discharged from QCH. You then attend appointments with your local GP, nurses and/or new adult service when required.

# Selecting an adult renal service that's right for you

There are several differences between the QCH kidney service and adult kidney services that are useful to talk about with your doctor. When choosing the best service for you, it could be useful asking about these topics.

## Your condition

Chronic Kidney Disease (CKD) is a disease that slows down how good your kidney is at cleaning your blood. CKD can be impacted by your genetics, other health conditions, medications and lifestyle choices like food and drinks. As you get older, it's important that you understand your CKD levels and what that means for your treatment to keep you as healthy as possible.

Stages of CKD and options		
CKD 1 and 2	60-100% function	If you have mild chronic kidney disease (CKD), stable kidney function (CKD 1 & 2) and only need 1-2 reviews/year, you might only need to see your GP. If your kidney function gets worse, your GP can then refer you to an adult kidney doctor.
		If you have mild kidney disease (CKD 1 & 2) and other health conditions, you may be transferred directly to an adult kidney doctor. Your QCH kidney doctor will discuss this with you.
CKD 3	30-60% function	If you have moderate kidney disease (CKD 3) or your kidney function isn't very stable you will be referred to an adult kidney doctor.
CKD 4 and 5	Less than 30% function	If you have more severe kidney disease (CKD 4 & 5), are on dialysis or have had a transplant, you will be referred to an adult kidney doctor and treating hospital (depending on your personal kidney function).

## Treatment options

As your kidney function slows down, there might be several different combinations of treatments to help keep you healthy. These include dialysis, kidney transplant, medications, and lifestyle choices. If you want to know more about what treatment might be like for you in the future, ask your kidney doctor and team, including your nurses, pharmacists, or dietitians.

## Private and public health services

Private services might have multiple kidney doctors you can choose to work with, but often have an extra cost each time you see them. Public hospitals and health services are free if you have a Medicare card. You will have a consultant kidney doctor, but you might also see different registrar and resident doctors. Registrars and residents rotate to different areas every couple of months, so you will see several doctors.

[Click here to read more about private and public health services.](#)







**Doctor-lead kidney service**



# Before you transfer

## How can I start getting comfortable in my new kidney service?

- **Ask your QCH transition coordinator for your new adult team's contact details.** These new contacts may be able to organise a quick tour of the renal ward, outpatient service or dialysis services. Ask your QCH team for these contacts: Case manager or CNC, Indigenous liaison officer (if relevant) and volunteer service.
- **If you live in a rural or remote area, ask for QCH transition coordinator for a patient travel coordinator at your new health service.** They can help you organise travel and accommodation and might be able to help reduce costs.
- **Call the hospital and ask to talk to the volunteer service,** or if you're Aboriginal and Torres strait islander, ask for an indigenous liaison officer. They can show you around the general parts of the hospital or health service.
- **Jump on google or ask the volunteer service about parking and transport.** Where are good places to park? What does it cost? Is there public transport nearby?
- **Take a look around the hospital.** Try to find these important places – outpatient waiting area, lifts, inpatient ward, pharmacy, food court, places to relax. Look for a hospital map to get a better idea of how to get around the hospital.

## Learning from the experts

There will be times when you start to feel like there are some aspects of your condition and treatment that you're not very confident about. This is a great opportunity ask your QCH kidney team for extra information.

Common things that people want more help understanding include medications, food and nutrition and how to balance life priorities, health and care. You might find it really helpful to ask your QCH transition coordinator to connect you with:

- **A pharmacist** – learn what different medications do, how to understand terminology used on medications, how to take different medications yourself and how to fill a script.
- **A dietitian** – learn how different foods and drinks impact your kidney health and how this can change over time.
- **A 'lived experience' support** – learn what transitioning and becoming an adult with kidney disease is like from someone who has been through it all themselves.

## What can I do to be ready for transition to adult services?

Adult services and hospitals help lots of new people with kidney conditions every day. They also look after more people compared to QCH. This means that you will need to be more in control of your own health and care than in QCH. There are lots of things that you can start to practice throughout your transition to improve your confidence with managing your care. These include:

- **Booking and changing appointments** by yourself.
- **Learning about your condition,** different tests and important health measures your team need to know about.
- **Learning how to explain your medical condition** to new doctors.
- **Writing down questions** to ask your doctor and team before your appointments.
- **Speaking up in appointments** and asking questions yourself (remember, there is no such thing as a silly question!).
- **Writing notes** in your appointments.
- **Attending appointments,** or part of your appointment without your family so you can ask your team questions.
- **Being involved in decisions** about your health and care.
- **Learning to do urine and blood tests without help** and with less pain relief.
- **Writing down and remembering your medications.**
- **Learning how to fill a script** at the pharmacy.
- **Knowing what to do in an emergency** or when you feel unwell.



# Differences between services

Differences between QCH and adult kidney services			
	QCH	ADULT SERVICES	TIPS
Your treating team	<ul style="list-style-type: none"> <li>You might be used to seeing the same kidney doctor, nurses, and allied health staff each visit.</li> <li>Your kidney doctor knows all about your condition and history.</li> </ul>	<ul style="list-style-type: none"> <li>Because adult services have many more patients and staff, you might see different team members each visit. Doctors often rotate between different teams and they may not have met you before.</li> <li>If you live in a rural/remote town, a nursing team might be your main carers.</li> </ul>	<ul style="list-style-type: none"> <li>It takes time to get used to the new service. Ask questions and let them know what's important to you.</li> <li>If your main carers are a nursing team, they will telehealth with kidney doctors when needed.</li> </ul>
GP	<ul style="list-style-type: none"> <li>You may have a GP you like and knows you well.</li> </ul>	<ul style="list-style-type: none"> <li>You will likely visit your GP more often for things like scripts, general health and mental health in between appointments with your kidney doctor.</li> <li>Your GP will help to communicate and coordinate your care with the hospital.</li> </ul>	<ul style="list-style-type: none"> <li>Find a suitable GP and stay connected with them through your transition process.</li> <li>Make sure your GP has been in contact with your QCH and adult renal doctors and teams.</li> <li>If you don't have a regular GP, try different doctors until you find one you like.</li> <li>Apply for your own Medicare card. This allows you to access healthcare on your own when you need to.</li> </ul>
Tests, treatments and procedures	<ul style="list-style-type: none"> <li>You might be used to having sedation or pain relief before procedures.</li> </ul>	<ul style="list-style-type: none"> <li>Sedation or pain relief might not be used for minor or routine procedures.</li> </ul>	<ul style="list-style-type: none"> <li>Discuss your pain medication needs with your team before transition and include it in your transition plan. E.g numbing cream before dialysis. You can also request psychology supports to assist with this.</li> </ul>
Communication	<ul style="list-style-type: none"> <li>Questions from your health care team might be directed towards your family.</li> <li>You might have practiced asking your own questions and seeing your doctor alone.</li> </ul>	<ul style="list-style-type: none"> <li>Questions about your health will be directed to you.</li> <li>You need to know about your condition.</li> <li>If you want support from another adult, the team must confirm you're okay with this first. However, decisions about your care must be made with you.</li> </ul>	<ul style="list-style-type: none"> <li>Practice seeing your doctor alone, asking questions and communicating your needs for several appointments to help you feel comfortable.</li> </ul>

Differences between QCH and adult kidney services			
	QCH	ADULT SERVICES	TIPS
People	<ul style="list-style-type: none"> <li>You will mainly have children and young people around you.</li> </ul>	<ul style="list-style-type: none"> <li>You’re likely going to be around much older people with many different backgrounds while you’re in the hospital.</li> </ul>	<ul style="list-style-type: none"> <li>Visit your new hospital before you transfer to see what it’s going to be like.</li> </ul>
Organisation	<ul style="list-style-type: none"> <li>If you live rurally, your family can travel with you to the hospital.</li> </ul>	<ul style="list-style-type: none"> <li>If you live rurally, the hospital might only be able to organise transport and accommodation for you.</li> <li>Instead of visiting the hospital, your local nurses might organise telehealth appointments with the hospital.</li> </ul>	<ul style="list-style-type: none"> <li>Call your patient travel coordinator at your adult service and organise with lots of time before your next visit.</li> </ul>
	<ul style="list-style-type: none"> <li>Your family might organise and manage your medications, ordering and payment.</li> </ul>	<ul style="list-style-type: none"> <li>You need to be responsible for taking medication and organising new scripts, ordering and payment.</li> </ul>	<ul style="list-style-type: none"> <li>Know medication names, their uses, and doses.</li> <li>Write these down in your phone notes or an app.</li> </ul>
	<ul style="list-style-type: none"> <li>Appointments and follow ups are usually organised through your family.</li> </ul>	<ul style="list-style-type: none"> <li>Appointments and follow ups need to be booked and organised by you.</li> </ul>	<ul style="list-style-type: none"> <li>Plan how you will get to your appointments.</li> <li>Allow lots of time to get to your appointment early.</li> </ul>

We hope that this guide will be helpful in managing your care and preparing for transition.

If you have any questions about your transition to adult services, please talk to the QCH kidney team.





# The best care for every Queensland child



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