



Your Transition from the Royal Children's Hospital to Adult Kidney Care

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This resource was developed under the guidance of the Kidney Health Australia Youth Program's Clinical Advisory Group

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- **Mr Stephen Cornish**, Kidney Health Australia Youth Program Manager
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Introduction

Your transition from The Royal Children's Hospital (RCH) to adult kidney care should be individualised, gradual and planned, addressing your health, wellbeing and other lifestyle needs.



This is an important process that you and your parents/carers will be involved in, alongside your nephrology and transition teams at the RCH, your adult nephrology team or adult nephrologist and your GP.

Your health care team will help you to develop new knowledge and skills as you become more responsible for your health. This process will take time and will empower you to confidently and actively prepare for your continued care.

As a young person receiving kidney care at the RCH, this brochure will give you a better understanding of what to expect in the adult health service. More information about transition and keeping well can also be found in the Transition and Transfer, Your move from Paediatric to Adult health care services brochure.

Why is this process different for each person?

Individualised transition

Everyone has a different health and life journey so having one way of preparing for transfer to adult care is not the best way for everyone. This is why it is very important that you talk to your health care and transition teams about what is best for you!

Not all kidney issues are the same and not all young people have the same kidney function or are on the same treatment or follow up program.

There are different stages of chronic kidney disease/function:

CKD-1	Normal kidney function but a known kidney abnormality.
CKD-2	Slightly abnormal but stable kidney function with a known kidney abnormality.
CKD3	3a - Approx. 45 – 60% of normal kidney function. 3b - 30-45% kidney function.
CKD-4	Approx. 15 – 30% kidney function.
CKD-5	Less than 15% kidney function (and usually requiring dialysis or kidney transplant).

The stage of your chronic kidney disease will determine the amount of treatment or appointments/reviews that you require.

Gradual transition

Transition should start during your early adolescent years and takes time. You should steadily learn to be independent with your health care as much as possible by the time you transfer to an adult health service. Your health care and transition teams will help you do this by helping you to learn new tasks, such as making your own appointments, and to learn more about your health each time you attend RCH. For example, most young people will start seeing the RCH nephrology team by themselves for part or all of their appointments before leaving the RCH.

Planned transition

Transition includes many steps and will help you to know what to expect when you eventually transfer to adult care. The time of transfer will be at a time that is appropriate for you. Most young people transfer when they have completed school or left school to start work. Some young people may transfer early if that is what they prefer or may need to stay a little longer (but usually before they are 19).

One of the important considerations in planning your transfer is deciding who will provide your adult kidney care. Your RCH nephrologist will discuss the best options with you. These options are detailed in the next section.

You will be referred for ongoing care to an adult nephrologist or your GP, depending on your kidney problem. Before you leave the RCH you will need to know who you are being referred to. It is best if you have met them prior to your final appointment at RCH. This helps to make sure that your health care follow-up is organised and that you don't miss out on important tests and medical reviews even if they are not often required. Meeting your adult health care team before you transfer also provides you with the opportunity to get to know them and for them to get to know you before you leave the RCH.

Your RCH nephrologist will need to include your direct contact details so it is important to make sure these details are correct. From the age of 16 and as a patient of the adult service, you (rather than your parents) will be the main point of contact due to confidentiality. Your new adult kidney care service will then organise an appointment for you.

When it's time to move to an adult health care service your RCH nephrologist will send a detailed letter and a comprehensive summary to your GP, new nephrologist or nephrology team. You may also request a USB with your relevant medical information from the RCH, from either the RCH nephrology team or the Transition Support Service.

Choosing the most appropriate adult kidney care service

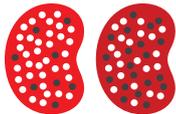
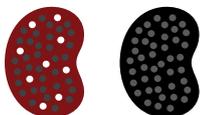
There will be differences between your paediatric nephrology service at the RCH and an adult nephrology service. Sometimes change can be challenging but these tips can help to make your transition to a new adult service/hospital a positive experience.

“ This is an exciting stage of your life as you become an adult and take charge of your own health. ”

As a young person leaving the care of the RCH, you may be provided with various adult nephrology service options. This will depend on the stage of your CKD (as explained above) and where you live (i.e. Melbourne Metro area, Victoria outside Metro area or Tasmania).

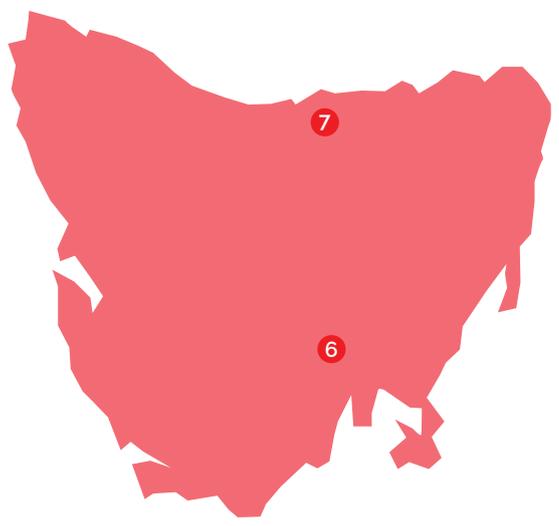
Stages of CKD and options

You may decide to access kidney care with a private nephrologist (you should discuss with your RCH nephrologist whether this is a good option for you).

Stages	Options
CKD 1 & 2	 <p>If you have mild kidney problems and stable kidney function (CKD-1 & 2) and only require 1 or 2 reviews per year it may be appropriate to just see your GP. If your kidney function declines, your GP will then refer you to a nephrologist.</p> <hr/> <p>For some patients that have mild kidney problems (CKD 1 & 2) and other health issues it may be best to be transferred directly to a nephrologist. Your RCH nephrologist will discuss this with you.</p>
CKD 3	 <p>If you have moderate (CKD 3) kidney problems and/or your kidney function is less stable you will be referred directly to an adult nephrologist.</p>
CKD 4 & 5	 <p>If you have greater than moderate kidney failure (CKD 4 & 5), are on dialysis or have a transplant you will be referred to a nephrologist and also a treating hospital (depending on the level of your kidney function).</p>



- Metropolitan Melbourne**
- 1 Royal Melbourne Hospital
 - 2 Austin Hospital
 - 3 St Vincent's Hospital
 - 4 Alfred Hospital
 - 5 Monash Medical Centre



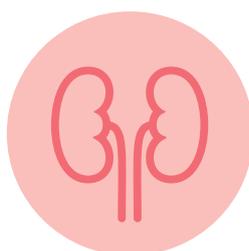
- Tasmania**
- 6 Royal Hobart Hospital
 - 7 Launceston Hospital

Location of services

There are many adult nephrologists across Victoria and in Tasmania. It is best to see one close to where you are living, studying or working in order to make it easy to attend appointments.



There are a number of hospitals in metropolitan or rural regions and community units that manage the care of adults who require dialysis, for example in Geelong, Shepparton, Bendigo and elsewhere.



Kidney transplants are only performed at The Royal Melbourne Hospital (RMH), The Austin Hospital, Monash Medical Centre (MMC), the Alfred Hospital and St Vincent's Hospital.

Some adults are cared for at these hospitals long term while some are referred there for transplant preparation, surgery and recovery and then transferred back to their local nephrologist for long term care.



If you are transferring to either the RMH or the Austin, you will be invited to one or two combined nephrology transition clinics at RCH.

An RCH nephrologist will introduce you to the adult nephrologist and nephrology nurse/s and sometimes social workers, who specialise in caring for young adults with chronic kidney disease at the hospital they work at. They will explain how things work in their service and you will have the opportunity to ask questions.

“Transition is an individual process and can look different for each young person.”

Funding assistance for patients who live in regional Victoria or Tasmania

If you live over 100km away from Melbourne and if your renal care is required to be in Melbourne, you may be able to access help with the cost of getting to and from your medical appointments.

Funding is only available for medical appointments and not for allied health or nursing visits. You can bring a support person with you too.

- If you live in regional Victoria, you can apply through the Victorian Patient Travel Assistance Service (VPTAS). The application form can be found here and signed by your nephrologist at your appointment <https://www2.health.vic.gov.au/hospitals-and-health-services/rural-health/vptas-how-to-apply>.
- If you live in Tasmania, visit the Patient Travel Assistance Scheme (PTAS) site for information and forms <https://www.dhhs.tas.gov.au/hospital/ptas>.

How will the Transition Support Service help me throughout the transition process?

During adolescence, you and your parents/carers will have discussions with your nephrology team about transition to adult care and you will be scheduled in to transition clinics at the RCH with the Transition Support Service.

This process will usually start when you are 15 years old and continue up until you transfer to adult healthcare. At these appointments, which are always scheduled alongside other clinical appointments or via telehealth for eligible patients, you will:

- Learn how to become more independent with your healthcare, as developmentally appropriate
- Know what to expect in an adult service
- Be linked in with other helpful supports to optimise your educational, social and psychological wellbeing.
- Be involved in developing and contributing to your transition plan and transition passport
- Receive support and assistance in coordinating your other care needs to adult services, if relevant

Differences between paediatric (RCH) and Adult Kidney Care

Here are some of the general differences you may come across, and tips on how you can be prepared for this change and be more independent with your health care.



YOUR TEAM		
Paediatric services	Adult services	Tips
<ul style="list-style-type: none"> You may be used to seeing the same nephrologist, nurse or allied health professional at each visit. Your nephrologist will know all about your condition. 	<ul style="list-style-type: none"> You may see different team members at your visits. There will be more registrars rotating frequently and who may be unfamiliar with you. Your adult nephrologist may need to develop more knowledge about your condition, especially if you have a rare diagnosis. 	<ul style="list-style-type: none"> It will take time for you to get to know your new adult team so ask questions and let them know what is important to you.



YOUR GENERAL PRACTITIONER (GP)		
Paediatric services	Adult services	Tips
<ul style="list-style-type: none"> Have a GP who you trust and who knows you. 	<ul style="list-style-type: none"> Your GP may become more involved and provide scripts in between appointments with your nephrologist Your GP is likely to be your main care coordinator. 	<ul style="list-style-type: none"> Stay connected with your GP throughout your time in paediatric and adult services. If you have a paediatrician before you transfer, see your GP regularly and make sure your GP knows about your care needs. If you don't have a regular GP, try different GPs in the practice until you find someone that you like.



TREATMENTS AND PROCEDURES

Paediatric services	Adult services	Tips
<ul style="list-style-type: none"> You may be used to having sedation before procedures. 	<ul style="list-style-type: none"> Different approach to procedures where sedation or general anaesthetic may not be used for minor procedures in routine practice. 	<ul style="list-style-type: none"> Discuss your sedation needs with your health care team and include this in your transition plan. You may like to request psychology or other supports to assist with this.



COMMUNICATIONS

Paediatric services	Adult services	Tips
<ul style="list-style-type: none"> Questions from your health care team may be directed to your parents/carers. You may have had some time alone with your nephrologist and practised asking your own questions. 	<ul style="list-style-type: none"> Questions about your health will be directed to you. You will need to know about your condition. If someone else wishes to speak on your behalf, the adult team will check that is OK with you. However, decisions about your plan of care must be agreed with you directly. 	<ul style="list-style-type: none"> Be confident and honest and don't be afraid to ask if you're unsure about anything. Prepare your questions before your appointment. You can bring someone with you to appointments or you can be seen on your own. Read your transfer letter to familiarise yourself with your medicines and medical history.



GETTING AROUND

Paediatric services	Adult services	Tips
<ul style="list-style-type: none"> You know where to go around the RCH. 	<ul style="list-style-type: none"> The adult hospital may be new to you. 	<ul style="list-style-type: none"> Visit your new adult hospital before you transfer. Check out the hospital's website for parking and general directions.



PEOPLE

Paediatric services	Adult services	Tips
<ul style="list-style-type: none"> You will mainly have children and young people around you. 	<ul style="list-style-type: none"> You're likely to be treated alongside much older people in outpatients and for your inpatient stays. 	<ul style="list-style-type: none"> Visit your new adult hospital before you transfer.



ADVOCACY

Paediatric services	Adult services	Tips
<ul style="list-style-type: none"> You may be used to seeing the same nephrologist, nurse or allied health staff member for many years. 	<ul style="list-style-type: none"> You may see different nephrologists because they may be on rotation at different times. Over time, you will become more familiar with the team. 	<ul style="list-style-type: none"> Know how to advocate for yourself and make the most of your appointments by being clear about your needs and how they can help you.



BEING INDEPENDENT WITH YOUR KIDNEY CARE

	Paediatric services	Adult services	Tips
Medications and treatments	<ul style="list-style-type: none"> Your parent/carer may manage most of your medications/ treatment, ordering and payment. 	<ul style="list-style-type: none"> You may need to organise your own medications and know when you need new scripts, including ordering and payment. 	<ul style="list-style-type: none"> Know what your medications are for and the ordering process. Most importantly, know who to contact. Have your own Medicare card. Use a phone app to help you organise your health care so you don't run out of medications unexpectedly as a refill script may not be immediately available.
Appointments	<ul style="list-style-type: none"> Appointment letters are usually sent to your parent/carer. Follow up appointments are usually organised by them too. 	<ul style="list-style-type: none"> Appointment letters will be sent to you. You will be responsible for booking and attending your appointments. 	<ul style="list-style-type: none"> Allow plenty of time to get to your appointment. Practise making your own appointments.

Glossary of terms

Nephrology - The branch of medicine that deals with the physiology and diseases of the kidneys.

Nephrologist - A doctor -who specializes in nephrology.

Your transition and transfer checklist and notes

Your team

Includes the following awesome amazing people:

My team members	Name/s	Notes
	My general practitioner	
	My kidney doctor	
	My transplant/renal nurse	
	My social / youth worker	
	My dietitian	
	My transition team member/s	
	Other	

My introductory meeting with my adult renal team:

Date	Who I met at this meeting	Actions to follow up

My first appointment with my adult renal team:

Date	Time	Type of appointment / who I am meeting with

This kidney clinic is located at:

Other appointments:

Date	Time	Type of appointment / who I am meeting with



I have a copy of my referral letter to the adult renal service

Your health

My kidney health condition in summary is:

My current medications and dosages and/or treatments:

My other health conditions (if applicable):

My allergies and how to manage them include:

My special dietary requirements include:

Tests I need to have and the date of my last test/s:

My emergency treatment action plan is:

My other important care considerations are:

Your resources

My contacts if I have questions or need support include:

Contact	Name	Phone number	E-mail
Transplant/renal nurse			
Social/youth worker			
Other			

My contacts if I am sick include:

Contact	Name	Phone number	E-mail
General practitioner			
Transplant/renal nurse			
Other			

And if I'm really, really sick:

Contact	Phone number
Ambulance	000
Emergency department	



I know about My Health support services, what they are for and how to use them...

- Medicare card and services
- Healthcare card
- MyGov account and services
- Private health insurance
- Other _____

More specific information about your new adult nephrology service will be provided to you before you transfer from the RCH by your RCH nephrology or transition team.

Contacts

RCH Transition Support Service

Visit: www.rch.org.au/transition

Email: Transition.support@rch.org.au

RCH Nephrology Department

Email: Nephrology.Dept@rch.org.au

Phone: (03) 9345 5054

Kidney Health Australia

Visit: kidney.org.au

Call: 1800 454 363

Email: Kidney.Helpline@kidney.org.au