

Transition Support Service

Take a deep breath for the future

Your continued cystic
fibrosis (CF) care

Introduction

Moving on from The Royal Children's Hospital (RCH) can be a scary thought for you and your parents/carers, so including and supporting you throughout this process is important, as it ensures that you are successfully linked in with your adult health care service for ongoing monitoring and care of your CF as you get older.

Your transition to adult care journey should be individualised, gradual and planned, and address your health, psychosocial and educational/ vocational needs. This is an important process that you and your parents/carers will be involved in, alongside your RCH CF team (and other RCH specialties) and the RCH Transition Support Service, in collaboration with either the Alfred Hospital or Monash Health CF teams.

As with the development of any new skill or change, this will take time and help you to identify strengths and learn new skills as you work towards greater ownership of your health and empower you to confidently navigate your continued care.

This brochure will give you a better understanding of what to expect in the adult healthcare setting and how you can actively prepare for the transfer.

Life at an adult hospital (The Alfred or Monash Health)

There may be many differences between the CF services at the RCH and adult healthcare. Sometimes change can be challenging but these tips can help make your transition to a new hospital a better experience. This is an exciting stage of your life as you become an adult and take charge of your own health.

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

Paediatric services	Adult services	Tips
Questions may be more directed towards your parent/carer and parents may answer your healthcare team on your behalf. Hopefully as part of the transition process at the RCH, you will have had an opportunity to have solo or part solo appointments with your doctor, and to practice asking your own questions.	Questions about your health will be directed to you. You will be expected to know important information about your condition and your current health status. 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. On your first visit your knowledge of CF and medical history are refreshed with you.	Be confident and honest in your answers and don't be afraid to ask if unsure about anything. It may be helpful to prepare your questions before your appointment and record this somewhere (e.g. your phone). You can always have someone with you or you can be seen on your own. Before you transfer, chat to your parent/carer and healthcare team about trying an appointment on your own with your doctor without your parent/carer.

Paediatric services	Adult services	Tips
You may be used to seeing one respiratory doctor for many years.	You are likely to see many different respiratory doctors because they may be on rotation at different times. Over time, you will become more familiar with the team.	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.
Your parent/carer may manage most of your medications, ordering and payment.	<p>You may need to organise your own medications and know when you need new scripts, including ordering and payment. If you consent, we are happy for your partner, parents or significant other to contact us on your behalf.</p> <p>You are welcome to send an email to request medications but allow a week for any script request made between clinic visits. You will need to arrange for someone to pick it up unless it is to be sent out.</p>	<p>Know what your medications are for and the ordering process. Most importantly, know who to contact and have their details recorded in your phone or somewhere handy.</p> <p>Make sure you have your own Medicare card or a copy of it.</p> <p>Some phone apps may help you to organise your medications and other aspects of your healthcare such as keeping track of appointments.</p>

Paediatric services	Adult services	Tips
Appointment letters are usually sent to your parent/carer. Follow up appointments are usually organised by them too.	Some adult services may send you a letter with a reminder text closer to the time of your appointment. Other adult services may only send you a reminder text and not a letter. You may need to make your own way to appointments and you will be responsible for booking and rescheduling appointments too.	<p>Allow plenty of time to get to your appointment and for the appointment itself.</p> <p>If you live over 100km away from Melbourne, you may be able to access transport assistance through the Victorian Patient Travel Assistance Service (VPTAS). Your doctor/nurse will need to sign this form for you.</p> <p>Know how to book and reschedule appointments and have these contact details with you.</p> <p>Practise making your own appointments and communicating with your healthcare team while at RCH. Do keep your parent/carer in the loop as much as possible.</p>

Paediatric services	Adult services	Tips
Appointments are likely to be more frequent.	<p>Appointments may be less frequent, unless you are unwell.</p> <p>Adult teams may not follow you up if you miss an appointment and if you run out of medication it takes a week for a new script to be written.</p> <p>You will be expected to contact adult teams to discuss any health concerns that you may have.</p>	<p>Keep track of your appointments and if you need to see the healthcare team before your scheduled appointment, call them as soon as possible.</p> <p>Be organised and make sure that you can attend your appointments. Do plan in advance and reschedule if you can't make an appointment as it may be more difficult to secure an appointment in the time frame that you would like.</p>
You know where to go around the RCH and will mainly have children and young people around you.	<p>The adult hospital may be new to you and you're likely to be surrounded by much older people.</p> <p>Visit the website to check the site map for parking and general directions. Call in at reception if you get lost on the way.</p> <p>You can be shown around at your first clinic visit, if you wish.</p>	You may like to visit your new adult healthcare service before your first specialist appointment, preferably before you transfer.

Paediatric services	Adult services	Tips
You may see other services and specialties at the RCH.	You may be referred to other services within the same adult hospital or be linked into services closer to home. You will need to keep track of these appointments yourself and know how these services operate as you will need to take an active role in coordinating these services to meet your needs.	Request services closer to home if possible and know how to get there, how they work and who to contact.
Services and equipment may cost less here.	The cost of equipment, tests and medications may be different. Ask the adult CF team about new tests or equipment they are recommending.	Ask about any extra costs at least a year before you transfer and if needed, access support through your RCH healthcare team if financial support is needed as this will allow time for the grant application.

Paediatric services	Adult services	Tips
<p>Hospital in the Home (HITH)/Wallaby – You may receive sedation for your intravenous access, and HITH involves daily nursing and physiotherapy visits.</p>	<p>Not everyone receives sedation for IV lines to be inserted but you can have a local anaesthetic for long lines in the radiology department. Let the team know if you need something to stop you being anxious going into a procedure. If you are going home with the Hospital in the Home Service, you may be trained yearly to administer your own IV medications using a portable pump (instead of a Baxter). However, you can request a Baxter if you prefer.</p> <p>Physiotherapy (airway clearance) is your responsibility and should be done as many times per day as recommended by the CF physios. They will also work out a program for you to do some exercise daily.</p>	<p>If you have difficulty with needles and invasive procedures, you may want to work on this with a psychologist before and/or after transfer to adult hospital.</p>

Paediatric services	Adult services	Tips
<p>As an inpatient, nurses will set up your physio and PEG feeds and will come to collect you for these sessions.</p>	<p>Your daily airway clearance and exercise program will be negotiated with you by the CF physios. You will be given an Alternative Menu that allows you to choose food other than those on the normal hospital menu. Supply of any additional nutritional supplements including PEG feeds will be discussed with the CF dietician when you come in. You are expected to hook yourself up to your feeds independently.</p>	<p>Know how to organise and coordinate your airway clearance, exercise, meals, insulin (if you have CFDR) and PEG feeds. If you are unsure, know who to contact for support if needed.</p>

Here are some of the more specific things that you may come across at The Alfred and Monash Health CF services:

	The RCH	The Alfred	Monash Health
Public transport	<p>Tram routes 55 and 59.</p> <p>Taxi rank at front of The RCH.</p>	<p>The Alfred is located at 55 Commercial Rd, Melbourne, 3004.</p> <p>Trams: from Swanston Street City. All trams except 8 and 1 travel along St Kilda Road. Tram 72 travels along Commercial Road, with a stop at the main entrance.</p> <p>Buses: Routes 216, 219 and 220 take you to the Alfred, 246 runs along Punt Road</p> <p>Trains: Prahran station is a short walk along Greville Street</p> <p>Taxi rank on Commercial Road.</p>	<p>Monash Health is located at 246 Clayton Road, Clayton.</p> <p>Buses: Routes 733, 703 and 631 and 630.</p> <p>Train: Cranbourne and Pakenham lines stop at Clayton Railway Station, located approximately 500m from Monash Health</p> <p>Taxi rank at front of the hospital.</p>

	The RCH	The Alfred	Monash Health
Car parking	<p>Car park available at a cost. Flat rate concession available on presentation of accepted concession card. Timed (and free) on street parking available.</p>	<p>Car park limited, at a cost. If you have a healthcare card or pension card, there is a special flat rate for 2 or more hours (only on weekdays). Validate parking at reception desk prior to payment at car park office. Meter and limited free on street parking available.</p>	<p>Car park available at a cost. Timed on street parking available.</p>
Referral	<p>Required from GP or other specialist.</p>	<p>Initial referral from a GP for ongoing CF care. The referral from your Paediatric Specialist/s only last for 3 months.</p>	<p>Initial referral from a GP received at or prior to your first clinic visit at Monash CF is required.</p>

	The RCH	The Alfred	Monash Health
Tests: Lung Function Tests, Oral Glucose Tolerance Tests, routine blood tests, x-rays, CT scans.	Routine tests are usually all completed on the same day.	Lung function, sputum microbiology every visit. Other clinical tests as required. Screening tests as frequently as recommended by the CF Standards of Care or as clinically indicated.	You will usually be booked in to have a lung function test prior to seeing your Consultant at your clinic appointment. A sputum culture will be collected at each visit and screening tests as clinically indicated or according to CF Standards of Care. Annual blood tests.
Review by consultant	Usually seen by the same primary CF Consultant or CF Fellow	Sometimes seen by different doctors if your primary CF Consultant is unavailable. You are usually allocated the consultant you met at the CF transfer clinic as your primary Consultant. You may see a specific Consultant if you are allocated to a clinic on the basis of Infection Prevention or you elect to come on a specific day.	You can request to see a specific doctor.

	The RCH	The Alfred	Monash Health
Expectations	Promotes gradual patient independence with family involvement.	Promotes patient independence as tolerated by patient or significant other.	Holistic family approach to CF care.
Staff	Team includes doctors, CF nurse coordinators, physiotherapists, dietitians, psychologist, social worker.	Team includes doctors, CF nurse coordinators, physiotherapists, occupational therapist, dietitians, psychologist, social worker, clinic coordinator, HITH nurses, community CF specialised nurses.	Team includes doctors, CF nurse coordinators, physiotherapists, dietitians, social worker, HITH nurses, community CF specialised nurses.
CF clinic days	Wednesday 'drop in', Thursday and Friday pm.	Alternate Tuesday am & clinics on 2 levels every 2nd pm, Wednesday, Thursday and telehealth clinic on a Friday am	Monday am and pm, Thursday am.
Telehealth	Telehealth consults are available for regional patients.	Telehealth consults are available for regional patients.	Telehealth consults are available for regional patients.

	The RCH	The Alfred	Monash Health
Inpatient expectations	Nurses will set up your physio and PEG feeds and will come to collect you for these sessions.	You are expected to agree to the treatment plan and be available to attend any treatments or procedures. You will also be asked to alert the CF team of any concerns promptly.	Your physio and PEG feeds may be optional and you are expected to attend to these independently without the direction and coordination of nursing staff.
Cross infection	Patients are asked to wear a mask in all 'common areas' of the hospital (not in the outpatient or inpatient rooms). All staff wear a plastic apron or gown for all patient interactions.	Outpatients are cohorted by time and sometimes in a different clinic area. Consideration of sputum micro-organisms is made when booking patients into clinics. Inpatients will be accommodated according to the Alfred Health Infection Prevention Draft Guidelines.	Patients are cohorted according to a colour coding process which identifies the bug each person has. You will only be booked in for appts with other patients with the same colour. An airway sample is requested at each visit. CF patients will be asked to wear a mask in all 'common areas' of the hospital (not in the outpatient/ inpatient rooms). CF healthcare staff will wear gowns and gloves for all outpatient and inpatient interactions.

	The RCH	The Alfred	Monash Health
IV access	IV access in theatre — can be done awake, with sedation or GA.	PICC inserted in medical imaging with local anaesthetic but no sedation unless requested.	PICC inserted in medical imaging with local anaesthetic but no sedation unless requested.
Hospital In The Home (HITH)	Daily nursing and physio if Melbourne metro. HITH outsourced for regional patients.	Antibiotics are self-administered. HITH may be outsourced depending on location. RDNS physio visits weekly if available.	Antibiotics can be self-administered, or you can access daily nursing if preferred. HITH may be outsourced depending on location. RDNS physio visits weekly. HITH outsourced for regional patients.
Regional CF clinics	Regional clinics in Albury, Geelong and Tasmania.	No regional clinics.	Combined adult/ paediatric clinic held in Sale twice a year.

	The RCH	The Alfred	Monash Health
Other		<p>Lung transplant unit on site.</p> <p>Referral to MMC or RWH for IVF, Obstetrics & Gynaecology. Routine Women's Health Clinic and Travel Clinics on site.</p> <p>You will be provided with an Emergency Contact/Medical Alert Card.</p>	<p>Pregnancy and IVF clinic on site.</p> <p>If at Monash, patients are referred to the Alfred lung transplant unit if required.</p>

Some common questions you may have regarding your transition

Q1: "How will the transition process work for me?"

You and your parents/carers will be participating in transition clinics at the RCH with members of your CF team (Transition Leads) and the Transition Support Service team. This process will start when you are 15 years old and continue up until you transfer to adult healthcare. At these appointments, which are always scheduled alongside your other clinical appointments:

- You will learn how to become more independent with your healthcare
- Know what to expect in an adult service
- Be linked in with other helpful supports to optimise your educational, social and psychological wellbeing.

As part of this process, you will have the opportunity to have solo or part-solo appointments with your doctors in Annual Review clinics.

When it's time to move to an adult healthcare service, you and your parents/carers will be invited to a special transfer clinic at the RCH with the CF team of your choice (either The Alfred or Monash), alongside your RCH team. At this clinic, you will meet your new care providers, learn more about how things work in this service and have the opportunity to ask questions.

Q2: “How will the adult healthcare service know about my medical history and will I have a copy of my medical information?”

Your RCH doctors and healthcare team will provide a comprehensive written summary of all your information to your new adult healthcare service. This information will be handed over and discussed in detail at the joint transfer clinic with your new care team.

You will also be provided with a USB with all your important medical information on the day of the transfer clinic.

Q3: “Do I have a say in where I am transferred to?”

You, your parents/carers and your RCH doctor will have a discussion about where your healthcare needs will be best catered for, before you transfer. This will also be discussed in your transition clinic appointments at the RCH.

Q4: “When will I be transferred?”

Your transfer from the RCH will occur on the day of the joint transfer clinic with your chosen adult healthcare service and officially you will have transferred, when you have your first appointment at either The Alfred or Monash Health CF service. If you don't receive an appointment within two months from the date of your transfer from the RCH, call your adult CF service and check your contact details to ensure that you have provided the current information to your new healthcare team. The RCH has an Access Policy which states that transfer should occur between the ages of 18 to 19 or earlier depending on your personal and/or educational/vocational circumstances. For most young people with CF, transfer occurs the year after you finish secondary school.

Q5: “How will I know I am ready to be transferred?”

- I understand and can confidently explain the cause of CF and how it affects different organs in my body
- I know and can list each of the therapies I am taking regularly (including airway clearance, nebulisers) and can explain why I am taking each of them
- I know and can list my medications, dosages and can explain why I am taking each of them
- I am responsible for (or working towards) remembering and administering my medications and treatment
- I know how to obtain scripts for medications and know how and where to fill a prescription
- I know who to call in the event of an exacerbation, and where to get advice on various CF issues as they arise
- I understand the risks of cross-infection and what precautions to take

- I know how my CF may impact on my reproductive health
- I know the effects of smoking, alcohol and drugs on my CF
- I know how to make appointments for the services I require
- I have a support network
- I have a General Practitioner close to home that I trust and feel comfortable with
- I have contributed to and discussed my transition plan with my CF team and the Transition Support Service team.

Some helpful resources

www.rch.org.au/transition

www.alfred.org.au/

www.monashhealth.org/

www.cysticfibrosis.org.au/vic/

www.spill.org

Adult CF service contact details

Alfred Health

55 Commercial Road, Melbourne, 3004

Telephone: **(03) 9076 3443** or **0418 596 938** (CF coordinators)
to discuss health issues during business hours.

Telephone: **(03) 9076 6960** or email **cysticfibrosis@alfred.org.au**
(CF Clinic Coordinator) for enquiries about appointments, medical
letters, forms, documentation relating to work or study and scripts.

Monash Health

246 Clayton Road, Clayton

Telephone: **(03) 9594 2915** (CF coordinator)
or **(03) 9594 2900** (appointments)

Email: **monashcf@monashhealth.org.au**



Take a deep breath for the future, your continued cystic fibrosis (CF) care
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www.cfv.org.au

Transition Support Service

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