



What to expect on your first admission
to hospital



Your first visit to hospital can be a less anxious time if you plan in advance and know something about what to expect. This booklet has been written to help families think about things that might happen during a hospital admission.

Talk to your child truthfully about what might happen before they come to hospital; if they are under school age, tell them just a few days before they come. Use simple words. If they are of school age, let them know a week or two in advance if you can. Let your kinder, childcare or school know why they will be away. There's no such thing as a silly question! Ask your CF team if you or your child need any answers.

Why do I need to come to hospital?

An admission, which is sometimes called a 'tune-up', is a shared decision between you and your CF team. Usually this is because your child will need intravenous antibiotics to help treat a bug that may be in your sputum in your lungs. The length of stay varies but is usually 10 to 14 days, but more or less depending on discussions with your CF team. Admission to hospital will usually be arranged at an outpatient appointment or over the phone with your consultant or the CF Nurse Coordinator. In most cases they are planned ahead to fit in with your lifestyle and allow the hospital time to allocate you a bed.

How do I get a bed?

Once you have talked about a hospital admission with your doctor or CF Nurse Coordinator, a date will be agreed and then;

- A request will be given to the Elective Bookings Coordinator or your child's name will be placed on the elective bed list.
- The CF nurse coordinator will follow up throughout the requested day and keep you updated as to when a bed is available
- If it is after hours the bed bureau will contact you to confirm a bed. If there is no bed available on the requested day, you will call bed bureau the following morning. Please note we do our best for you to be admitted on the requested day but sometimes it does not happen.
- If your child is very unwell or needs treatment straight away, you may need to go to the hospital Emergency Department. Please ask the doctor you see there to contact either the CF Care Coordinator (9594 2915) or Paediatric Respiratory Consultant on call after hours so that we can coordinate your child's care. We will do our best to admit you directly to the ward.



- Children and teenagers are admitted to 3A Forest, 4A Canopy or 4B Aviary on the third and fourth floors of the Monash Children's hospital. Parents are welcome to visit or stay with their child throughout the day and night. On each ward, you and your child will participate in Family Centered Care.

Family Centered Care

It's a philosophy about caring which shapes paediatric nursing within Monash Health. You know your child's needs better than anyone, so you are a very important part of the team looking after your child in hospital. You might like to write a comfort plan – special things or items that soothes your child, their likes and dislikes. You can see more information about your child's visit to hospital at the Monash Children's website at <https://monashchildrenshospital.org/patients-and-families/your-childs-stay/before-your-stay/>

Rights and Responsibilities

As a patient or parent/guardian of a child undergoing or receiving health care and treatment by our Hospital you need to know what to expect from these services and its staff. It is also important that you understand what your responsibilities are when receiving these services at one of our facilities. You can see more at <https://monashchildrenshospital.org/patients-and-families/rights-and-responsibilities/what-you-can-expect-from-us/>

What Should I bring with me?

- Medications, including pancreatic enzymes, vitamins, antibiotics, Pulmozyme and any other medications you take
- Favourite food or snacks, the kitchen will supply meals and snacks for your child but unfortunately no meals are offered for parents. You may bring your own food in and store in the family room. There is tea, coffee and cow's milk for you to use. There is a microwave, fridge and dishwasher also.



- Physiotherapy equipment (ie. PEP, Flutter, acapella etc.) and your Pari nebulizer (mouthpiece and tubing)
- Running shoes and exercise clothing for physio and comfortable changes of clothes to wear during the day as well as pajamas and your toiletries.
- Mask! Remember to bring your child's mask so they can put in on as you are entering the hospital.
- On the ward: The paediatric wards; 3A Forest, 4A Canopy and 4B Aviary have books and a playroom as well as therapists and educational support on the wards. Younger children might need nappies or 'pull-ups'. You might like to bring your own pillow, blanket or doona from home. You might like to bring some things from home like a special toy, books, games, music, laptop (don't forget your charger) or even schoolwork. The teachers in the Monash Children's Hospital School can help your child with their school work and help them stay in touch with their school class.



When I arrive



Parking

Enter the carpark from Clayton Rd. Monash Medical Centre and the Monash Children's Hospital share the same car park. You can purchase a daily or weekly ticket. Weekly tickets are cheaper if you know you are going to have a longer stay. Concessions may be available for concession card holders and are available from the cashiers Monday to Friday. Families are entitled to a 20% reimbursement program from CF Community Care. You must pay upfront and provide the receipts to CF Community Care. The reimbursement is capped at a certain amount. Speak with your social worker to obtain an application form.

Private health Insurance

You may be asked if you have or want to use private health insurance. If you do, there will be no out-of-pocket expenses. You can read more at <https://monashchildrenshospital.org/patients-and-families/billing-and-insurance/>

Visiting

Parents are welcome to be with their child at all times, but other visitors should limit their visiting times to between 8am and 8pm. On Aviary ward there is a rest period from 1-3pm where we ask visitors to be supportive of patient's rest time.

Your CF team when you are in hospital

- Nursing staff
- Junior ward doctors (the Resident and Registrar)
- Consultant
- Allied health team
 - physiotherapist
 - dietitian
 - social worker
 - child life therapy
 - creative arts
 - music therapists
- As a parent, you are your child's advocate and know your child the best. It's okay to talk through any issues with the nursing staff or



the junior ward doctors first. Most doctors' rounds are conducted in the mornings, but we cannot guarantee the time that the doctor will visit for a review. The paediatric consultant ward rounds occur twice per week, on Monday afternoons and Thursday mornings.

If at some stage you wish to talk with a Consultant regarding your child's treatment, please ask the nursing staff or junior doctors to contact the Consultant to arrange an appropriate time to meet. All will be done to ensure that you are kept up-to-date with your child's prognosis and ongoing care. If you have any practical, financial or emotional issues, you can ask to talk to the CF social worker.

Arriving on the ward

When your child is admitted, the nurse will go through the admission questions about your child's past medical history, allergies, diet, medication regime as well as taking your contact details. You may feel like you are repeating yourself but the nurses need to make sure all information is correct. They will explain what will happen with your first admission and what to expect.



The nurses will show you how to use the television and meal ordering system in your room and show you around the ward to the parent lounge and tea and coffee facilities. Where possible, your involvement in their care will be discussed with the nurse at the beginning of each shift, who will take into account changes in your child's condition and nursing care. If you would like to assist in the care of your child, your nurse will be there to teach and support you until you feel confident. Being involved in your child's care is important, however, when you need to take a break you are encouraged to do so.

Once the nursing admission is completed they will contact the respiratory doctors to come and review your child, decide on which antibiotics to give and answer any medical questions you may have. Your consultant may not be on the ward the day you arrive but the resident or registrar will discuss any medical or other issues with

your consultant. Within the first couple of days, the allied health team will review you, and the physiotherapists will make a time to see you twice a day.

Monash Children's is a teaching hospital and students often attend ward rounds. If you or your child are new to hospital, you may choose for them not to attend.

Cross infection

Your child will be in a single room. Please be aware that there may be other children on the ward who have CF and this is important to keep in mind especially when accessing shared play areas such as the Starlight room or play room. Some CF children may have certain bugs and may be unable to go into the Starlight room, movies or Radio Lollipop. Please only attend to your child's needs. If another child needs assistance, please call a nurse to assist.

For more information please ask your nurse.

Food and nutrition

Menus are available on the television in your room. You can order your child's meals via the online system and the orders will be sent to the kitchen. You must order at least an hour prior to meal times. Breakfast arrives around 7:30am, lunch at 12noon, and dinner at 5.30pm. On the children's wards we have a snack trolley that will come around to your room at 10am and 2:15pm daily. Snacks such as fresh fruit, flavoured milks, tiny teddies, cheese and biscuits, sultanas and sweet biscuits are on offer.

Your nurse and dietitian ensure you are able to order higher calorie foods such as eggs for breakfast. Your dietitian may also talk about oral nutritional supplements – these are high energy drinks or powders. You may or may not have already been on these at home.

If your child is on a milk formula please let the staff know on admission so that we can order the formula for you. Some less common formulas may not be available, and you will need to supply your own.

If your child is taking pancreatic enzymes, it is important to bring these in with you from home so that there is no delay when your first meal or snack arrives! If your child requires assistance with taking enzymes and there will be no parents or carers with your child during their stay, it is important that you let your dietitian know so that

they can discuss enzyme dosing with nursing staff. If you have any 'enzyme guides', you could leave these at your child's bedside – this will help nursing staff aim for the correct enzyme dose.

Parent's and carer's meals

Meals can be purchased from Gigil Cafe in the Monash Children's Hospital or from Mr. Clayton's cafe in Monash Medical Centre. There are also a limited amount of vending machines with frozen meals available. Meals can be re-heated in the Parents room or Ronald McDonald Family room as well. For breastfeeding mothers, meals are provided from the hospital's kitchen. There is a parents' room with tea/coffee making facilities, fridge and microwave. You might consider bringing breakfast cereal or pre-prepared meals in for your stay.

Ronald McDonald Family Room – Level 4

Ronald McDonald Family Room is run by volunteers and is a space away from the wards that has cooking, bathroom and laundry facilities as well as internet access for parents and relaxation spaces. They have some supplies of toiletries as well as donated food and meals, tea and coffee.

Procedures

You will most likely have a few procedures while in hospital. Some you may have had before and some may be completely new.

Blood test: For babies we take blood from their heel. Once they are of walking age we tend to do a simple finger prick and collect the blood in a small tube. Blood tests may be required daily depending on which antibiotic you are on. For example, blood tests are required for all children treated with the antibiotic Tobramycin.

Stool sample: We may need to obtain a stool sample to assess the amount of fat and malabsorption that might be present.

Intravenous Cannula (IVC): Either a peripheral or a long line will be inserted for your child's antibiotics. Numbing cream is applied to the skin 30 to 60 minutes before the line is inserted; a calming medicine or nitrous oxide can also be used to help children feel more relaxed about the procedure. For children younger than eight

years of age, a short, general anaesthetic may be administered, as this enables the line to be inserted quickly and with minimal trauma to your child. If this is the case, your child will be required to fast prior to the procedure with no solids for six hours, and no fluids for four hours prior to the anaesthetic.

PICC line: A PICC [Peripherally Inserted Central Catheter] line is a long intravenous device that is usually used for older children and adolescents. It is a central line that is inserted into the arm and the end sits in one of the large veins in the heart.

Lung Function Test: A lung function test, (also called Spirometry), is a non-invasive test that is performed to assess and monitor someone's lung capacity and function. It is performed via a portable laptop computer device [in the out-patient clinic] or in the Monash Lung and Sleep Department. It is the measurement of forced expiration to assess the volume of air in the lungs (forced vital capacity) and the airway calibre, (forced expiratory volume in 1 second).



Hospital Entertainment

Playroom

Forest and Canopy each have a playroom. The playrooms are thought of as “safe areas” for children where they can relax in a friendly, fun environment – so no medical or nursing procedures are allowed to take place in these rooms. We ask that no food or drinks be consumed in the playrooms and mobile phones and cameras are not to be used. Children under five years must have an adult with them.

Television/telephone

Free to air and limited Foxtel services are available to all patients free of charge. There are also games that you can play on the TV and the ability to make phone calls between rooms.

Department of Art, Music and Child Life Therapy

The department includes our art therapists, music therapists and child life therapists. It provides age appropriate and interesting play, art or music equipment for children at their bedside. They are available on the wards for children of all ages from infants through to adolescents during the week.

Art Therapy



Art Therapy (AT) improves the patient experience by reducing anxiety and stress and addressing patients concerns associated with their hospital admission through the use of visual and creative expression. The Art Therapy team offers an Individual service, at the bedside or in an activity room across the wards of the Monash Children's Hospital.

- Uses a wide variety of art materials for self-expression such as pencils, paint, clay, 3-dimensional materials and wool.
- Mindfulness and visualization activities to assist with relaxation, sleep and stressful events.
- You don't have to be good at art to do art therapy; it is simply another way to express yourself and your experience.
- Can assist with: expressing emotions, helping to make sense of things; distraction to relieve anxiety; relaxation to help with discomfort or pain; learning new skills; feeling normal in a hospital environment.
- Arts Therapists can be with patients at medical procedures if requested to help with anxiety and pain.



Music therapy

Music Therapists use music to engage patients and their families both individually and in groups during a hospital admissions. Children and adolescents sometimes experience anxiety, fear or a general lack of control when hospitalized. Music therapy can address these needs and more, by providing opportunities for patients to make independent choices and express themselves. Our therapists use a variety of interventions to help children and adolescents feel supported such as

- Singing
- Deep breathing
- Learning an instrument
- Recording
- Lyric writing
- Playlist creation for mood support or exercise/physiotherapy



Music is an effective and enjoyable medium that can assist in decreasing anxiety and pain, support chest-physio with singing, and provide an emotional outlet or distract a patient during medical procedures. Patients need no prior music experience or music ability to benefit from music therapy! Services are available Monday to Friday and we run a group for younger patients on Wednesdays at 10.30am in the playroom on 4A Canopy. We also have a music library service that enables patients to borrow music instruments, headphones or iPods.

If you are interested in meeting a music therapist, please let one of your nurses or CF staff know

Child Life therapy

Supports a patient's emotional wellbeing and assists children in coping with their hospital Journey. Child Life Therapists provide procedural pain support which includes education and techniques to prepare for medical procedures and distraction therapy during a procedure. Child Life therapists also provide positive play experiences during hospital admission. Child Life therapy team can be contacted by your nurse. Play Therapists provide a range of activities and diversions for patients in either playrooms or by the bedside.

Each child is visited daily by the Play Therapist and activities are planned that are developmentally appropriate and, most importantly, enjoyable!

Starlight Room – Level 4

We are fortunate to have “Captain Starlight” from the Starlight Foundation visit the children’s wards on a regular basis to entertain patients with a host of special activities. The Starlight Room is on the 4th floor and is open every day from 10am-4pm. It is useful to check whether there are other CF patients using the Starlight Room before you go. In some cases you may not be able to attend the starlight room, but the starlight captains can come to your room!



Radio Lollipop – level 2



Radio Lollipop provides craft activities and games for patients at their bedside as well as in their radio studio on level 2. They are available on Mondays and Wednesdays from 6pm-7:30pm and on Sundays from 9:30am-11am. You will be able to request songs and listen from the foyer or through the TV in your room.

Hoyts - level 3

There is a Hoyts cinema that plays movies twice a day every day except Sunday. You can book a session through your nurse or ward clerk.



Monash Children's School



The Monash Children's Hospital School delivers education services alongside a patient's treatment, recovery and reintegration into their school. It supports patients with significant health conditions who are at-risk of disengaging from education, or who are unable to attend their regular educational setting due to their health condition. The school provides educational experiences and outcomes that children and young people would have

had, if they had not been experiencing a significant health condition. Our team work closely with the young person, their families and their regular school or educational setting to enable this.

Pastoral care

Offers holistic and compassionate care to patients and their families. You may receive a visit on the ward to clarify if you want pastoral services and which faith would be required. Volunteers can provide bedside visiting with your signed consent. A multi-faith Chapel is located close to the Department of Respiratory and Sleep Medicine on the second floor of Monash Medical Centre. It is a quiet space anyone can attend. Anglican Eucharist is 12.30pm every Tuesday and Catholic Mass is on Thursday 12.30pm.

Other Services

Cystic Fibrosis Community Care has financial assistance and support programs. They are usually happy to come and visit while you are in hospital. This is a great opportunity to meet the CFCC team and find out what services you can access for being a member. For information, please phone 9686 1811.

Ronald McDonald House is situated at the back of the Monash Children's Hospital and is available for families to stay overnight closer to the hospital during an admission. The rooms are available for everyone but prioritised for families living over 100kms away from the hospital. There is a fee per night depending on your location. If you think you need a room for your family you may speak with your nurse or CF coordinator.

Discharge from hospital

Discharge from hospital can be a time of mixed emotions where parents are pleased to be taking their child home yet concerned about the care they may need in the early days of recovery. Please contact your nurse or CF Coordinator if you have any concerns about their care. Children sometimes may need time to adjust to their usual routines once at home again. On the day of discharge you may need to wait for certain medications or paperwork. It is important to remember that there isn't a set discharge time.

You may need to wait for:

Medications from pharmacy need to have a script written and sometimes this can only be done on the day of discharge. If you know of a regular medication that you need on discharge inform your doctors earlier in your admission.

Blood results may need to be back prior to leaving. They usually only take an hour or two.

Last dose of intravenous antibiotics you may need one final dose of antibiotics prior to leaving which may be in the afternoon. In this case you will have to wait until this is complete before getting discharged.

Hospital in the Home may be organized for you to complete a number of days of antibiotics at home. There is a specific criteria that has to be met, which depends on the type of antibiotic, length of treatment and also your location.

Paperwork such as a discharge summary will be sent out to you and your GP in the mail. Nursing staff will give you a 'discharge passport' that explains your discharge and follow up instructions. Your CF team will continue to follow your child's progress through your regular outpatient appointments.



