

## USEFUL CONTACTS

Head of CF service	Prof John Wilson	9076-2315	
General Enquires	Merrilyn	9076-2315	
Nurse coordinators	Felicity & Elyssa	9076-3443 or 0418-596-938	- Health related questions
Clinic coordinator	Libby	9076-6960 or L.Francis@alfred.org.au	- Clinic appointments & scripts
Senior physiotherapist	Brenda	9076-2000 Page 4601	
Dietician	Audrey	9076-3063 Page 4122	- Supplements or dietary questions
Social Worker	Mary	9076-3026 Page 4432	
Occupational Therapist	Jenny-Maree	9076-3526 Page 4037	
Psychologist	Maxine	9076- 3805	
Ward 5E		9076-3651	
Alfred @ Home		9076-6985	
Patient & Community Advocate		9076-3028	

# CYSTIC FIBROSIS

care at The Alfred.

A guide for living well with CF.



**TheAlfred**

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Medicine, The Alfred, Melbourne. 2011

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## FREQUENTLY ASKED QUESTIONS ??

**Need to change a clinic appointment?** Call Libby—9076-6960 or email—[l.francis@alfred.org.au](mailto:l.francis@alfred.org.au)

**Worried about your health in some way?** Call the nurse coordinators—Felicity & Elyssa on 9076-3443 or mobile 0418-596-938

**Need any type of form filled out?** Bring it to your next appointment

**Running out of medications?** Either bring your clinic appointment forward, see your GP, or call / email Libby. (allow 1 week for script)

**You have sudden onset flu like symptoms?** Call the nurses—the earlier you start on anti-viral's, the better the outcomes.

**Running out of supplements?** Call the Nutrition department —9076-3063

**Having financial difficulties?** Talk to Mary our CF Social Worker, or chat to the CFV team about how they could help out.

**Role of the On Call Registrar?** The Registrar that is available 24 hours a day is for Emergency situations only. If you become unwell suddenly out of hours or on the weekend, it is appropriate to call them via switch—9076-2000.

It is not appropriate to call them for scripts or general advice that could wait until the next business day, or a clinic appointment.

**Health issues that are not CF related?** If you have a serious health concern, that you don't think its CF-related, we still prefer you come to the Alfred for treatment. We ensure that your CF needs are met, while attending to the other problem.

## CYSTIC FIBROSIS VICTORIA—SERVICES & PROGRAMMES

Cystic Fibrosis Victoria is an organisation that provides a range of support programs and services to clients with CF that aim to enhance their quality of life and meet their needs. To be eligible to access the services and programs, you must have CF and be a current member.

### Support Services & Programs:

- Δ **Advocacy Support & Lobbying**—CFV advocates for members on a local, state & national level and liaises with other organisations to lobby for improved benefits for those with CF.
- Δ **Accommodation assistance**—CFV provides assistance with accommodation for people living in rural and regional areas.
- Δ **Counselling & Referral**—qualified support workers offer counselling and referral services as needed
- Δ **Fitness Participation Program**—promotes physical fitness through provision of grants to assist people with CF to purchase sporting / fitness equipment.
- Δ **Financial Assistance Program**—for both CF related costs & emergency relief.
- Δ **Holiday cabins**
- Δ **Hospital & Home visiting program**—for support
- Δ **Information Services**—Education forums, chat room, resource material
- Δ **Memorial Service**—occurs annually
- Δ **Outreach support programs**—networking and support meetings for people living in similar areas.
- Δ **Parents activities**— for support and guidance
- Δ **Physiotherapy Equipment Program**— subsidises buying new equipment.  
Equipment borrowing program also available
- Δ **Regular Newsletters**
- Δ **Scholarship Program**—offers support to adults with CF through assistance with payment for short courses & educational opportunities that will improve their chances of securing employment.
- Δ **Support Group Facilitation**—CFV provides networking opportunities for those in similar situations such as grandparents, siblings and parents with a newly diagnosed child
- Δ **Subsidy Benefits**— Access to discounted multivitamins (VitABDECK) and salt tablet. Free Hospital TV Hire.

## INTROCUCTION

The Alfred is a large teaching hospital that provides health care services to 300,000 Victorians each year. The Alfred has the widest range of adult specialist services in Victoria and is also a leading research institution.

The first few adults with cystic fibrosis came from the Royal Children's Hospital in the late 1970's. Since this time the CF specialist team has grown to include 3 specialist physicians, 2 nurse coordinators, physiotherapists, dieticians, an occupational therapist, social worker, psychologist, psychiatrist, clinic coordinator and community CF specialised nurses and physiotherapist. The Alfred is a designated CF centre of Excellence, and provides world class care to almost 300 people with CF.

## Our Aim

The CF specialist medical, nursing and allied health team endeavour to meet your individual health needs at all times.

We are dedicated to providing adults with CF access to the best available medical, nursing and allied health care in order to preserve and enhance your best possible quality of life.

The members of the CF team who you see in the outpatient clinic will also be responsible for your management in hospital and work closely with the ward medical and nursing staff.

We welcome feedback and comments and look forward to getting to know you and your family.



### The Multi-disciplinary team approach

The responsibility for your health management ultimately rests with the CF specialist (Consultant). However, many years of research and experience has shown us that a multi-disciplinary approach to care is often the most helpful for people with CF. When you are in hospital, you will meet a number of health care professionals who have different, but complimentary, skills and qualifications all aimed at providing you with the best overall health care.

### The hospital care team

There is only one Consultant on duty on the wards at any given time, who may not be your usual doctor. Because we work as a team, your CF doctor will remain involved in your care and be kept informed of your progress.

Other people you may meet include:

- **Consultant doctors**, nurses and allied health staff from other specialties e.g.: Endocrinologist & Diabetes Educators, Gastroenterologists, Radiologists, Anaesthetists, Lung Transplant Team.
- **CF Registrar**: The Doctor on the ward who makes the day to day assessment of your progress and decides on your medical management. He or she is in contact with the CF consultant and works closely with the doctors and nurses.
- **CF resident**: The doctor on the ward responsible for ensuring that you have tests, medications and procedures you require. They also work closely with the care coordinators, your nurses and the CF team.
- **CF coordinator**: The CF nurse who provides continuity between your outpatient and inpatient care by assisting the ward medical and nursing staff to liaise with the CF team. The role of the CF coordinator includes being the first point of contact for you if you are worried about your health and is involved in arranging an admission to hospital.
- **Resource Nurse**: An experienced member of nursing staff responsible for patient care and coordination for the shift.

## THE STUFF YOU DON'T WANT TO TALK TO MUM / DAD ABOUT

There are some common misconceptions about the birds and the bees in people with CF.

Men with CF do produce sperm and have the same amount of hormone production as men without CF. eg: Testosterone. While most (98%) of men with CF lack the tube that connects the testicles to the outside world. Some men are fertile, so precautions need to be used to prevent unwanted pregnancies, or STD's. IE: USE CONDOMS!

Women with CF do not have any structural issues that prevent pregnancy. In some cases, the secretions in the cervix can be thick, and make it difficult for sperm to pass through.

Having to deal with a chronic illness is a time consuming job—be sure to remember to have regular pap smears. All sexually active women should have a pap smear every 2 years.

If you have more questions, feel free to chat to anyone in the team you feel comfortable with, or visit your GP or closest sexual health clinic.

## FAMILY PLANNING

Whether you are male or female and are considering starting a family, there is a list of things to think about.

We have a geneticist linked with the CF service who is involved with the first steps of planning a family, including carrier testing your partner.

For the men, an andrologist looks after the sperm retrieval side of conceiving. There are multiple hospitals around Melbourne who specialise in IVF (In vitro fertilisation). We will refer you towards the hospital and Doctors that best suit your needs.

For the ladies with CF who are considering carrying a child, there are obviously more potential health risks. We look at optimising your lung function, weight, and diabetes control before conceiving. The best outcomes are seen in people with lung function over 60%. We link you in with an obstetrician who is experienced in managing women with CF, and associated with an 'at risk' delivery service. Feel free to ask your Doctor if you have any questions.

## FLU

### Symptoms of the Flu:

- Fevers / Temperatures—over 38 degrees Celsius
- Increased / irritating cough
- All over body / joint aches
- Runny / stuffy nose / sore throat / headache
- Nausea / Vomiting / diarrhoea

If in doubt call the nurse coordinators to talk over your symptoms. The earlier the intervention, the less impact the flu can have. **Tamiflu is best started within 48 hours of symptoms starting.** If you are in clinic we will perform a swab to test for the strain of the flu.

**Infectious period:** One day before symptoms, up to 7 days after they start.

**Prevention:** Try not to touch your face (eyes/nose/mouth), as this is where the germs enter your body. Hand Hygiene is your best friend.

**Flu vaccine:** Supply usually becomes available, in March / April each year. You can obtain the vaccination for free from your GP or in CF clinic.

## CF RELATED DIABETES

In CF, the pancreas functions at about 50% compared to that of a person without CF. It is for this reason that people with CF have an increased chance of developing diabetes. CF related diabetes is unlike insulin dependant diabetes, and type II diabetes. It is an entity unto itself. Up to 50% of people with CF will have diabetes by the time they are 30.

Uncontrolled blood sugar levels can make it difficult to fight a chest infection. There is a correlation between poor diabetes control and loss of lung function.

**Symptoms of new diabetes:** Loss of weight, a thirst that cannot be satisfied, passing lots of urine, a sweat smelling breath. Sometimes these symptoms come all of a sudden, sometimes they creep up on you.

**What to do?** Call the nurse coordinators to discuss your symptoms. Most GP offices can do a finger prick test to check your blood sugar. We do regular testing of you HbA1C—which looks at your average blood sugar over the last 3 months.

**How to prevent diabetes?** Sometimes it is inevitable that you will get diabetes. To prevent stressing your body—it is best to spread your sugar intake out over the day. Rather than having a huge amount all at the same time.

- **Nurse Manager:** Nurse responsible for effective operation of the ward and managing the nursing staff.
- **Registered and Enrolled nursing:** Each shift a different nurse will be assigned to care for you. They will administer you IV's, care for your line, offer support and answer questions. Nursing shifts are: 7am—3:30pm. 1pm—9:30pm & 9pm—7:30am.
- **Physiotherapists:** The physiotherapists will review and advise on the most effective airway clearance technique/s and exercise program to help you get back to your best. Be sure to discuss any aches and pains you have with your physio before commencing treatment.
- **Dietitian:** The dietitian will review your nutritional requirements and assist you to meet these while on the ward.
- **Occupational Therapist:** Can assist in setting and achieving goals of any size. OT can also assist in vocational support and guidance.
- **Social Worker:** Assists you and your family to deal with processes and issues associated with your experience of being in hospital. This may include short term and crisis counselling or family therapy. The social worker can also act as a link between hospital and community and facilitate your access to specialist agencies and resources.
- **Psychologist:** May provide specialised counselling to help you and your family / partner deal with particularly difficult challenges, issues or feelings associated with having CF.
- **Psychiatrist:** Provides specialist opinion and treatment, where necessary, for mental health issues.
- **Pharmacist:** Reviews your medications and provides education to optimise outcome of your treatment.
- **Hospital in the Home clinical liaison nurse:** Responsible for assessing and organising the necessary supports for you when you are referred to the Alfred Health Hospital in the Home program for treatment outside of the hospital.
- **RDNS CF Home Support Team:** Can provide special CF nursing and physiotherapy monitoring and assistance to you at home.

## THE TREATMENT GOAL

The aim of treatment is to assist you to regain and maintain your best possible outcome.

## TREATMENT PLANS—Getting involved

The aim of treating you in hospital is to ensure that you receive the level of care you need promptly and efficiently. This means that you should only need to stay for as long as it takes for you to be well enough to care for yourself at home. The duration of your treatment may vary from one visit to the next. This depends on; how unwell you are at the start of your treatment and what happens along the way. Your progress is monitored on a daily basis by the ward medical and nursing staff in close consultation with the CF team. Your participation and cooperation is essential to the success of your treatment. If there are aspects of your plan that are unclear please ask for an explanation.

## What you can expect from US ??

- To provide best practice, evidence based treatment for cystic fibrosis.
- To work towards creating a therapeutic alliance with you that results in a working health care partnership.
- To provide opportunities for you to develop and improve your individual health maintenance strategies.
- To provide you and your carers with information that allows you to participate in, and make informed choices about your management

## What we hope from you ??

- To participate in discussions and decisions about your treatment.
- To ask for assistance with, or information about, any aspect of your care.
- To make yourself available at agreed times for physiotherapy and gym sessions.
- To attend meetings, investigations & procedures at times specified by the service provider.
- To communicate any concerns, problems or differences of opinion to the relevant staff member promptly.
- To return from any leave by 10pm, and not to consume alcohol while out.

## PNEUMOTHORAX

A pneumothorax occurs when air gets stuck in the wrong part of your chest. Pneumothoraces rarely occur in people with moderate to normal lung function. The likelihood increases as your lung function declines.

**Symptoms:** Symptoms vary. Some people experience a sudden onset of pain, and difficulty breathing. Other times the pain can come on gradually over hours. It may be felt high around the shoulder tip.

If you suspect something other than a chest infection, call the nurse coordinators to discuss your symptoms. We may get you in to clinic for a chest X-ray and medical review. Once again, early intervention can prevent further problems.

If the pain is sudden, call an ambulance, and ask to be taken to the Alfred if at all possible. If you have a loved one with you—get them to call ahead and let us know you are on your way.

## BOWEL BLOCKAGES

The next most common complication in CF after chest infections is bowel blockages, otherwise known as a bowel obstruction. Sticky secretions in your gut, combined with swallowing sputum, can cause a 'rock' to develop in your bowel.

**Symptoms:** New abdominal pain. Sharp in nature. Not opening your bowels as often as you normally would. Bloating, and a decreased amount of wind being passed.

**What to do?** During business hours, call the nurse coordinators to discuss your symptoms. Sometimes the problem can be fixed with medications at home. Otherwise an admission is required to rehydration and to clear the blockage. We always endeavour to prevent the need for surgery.

**How to prevent blockages?** Stay well hydrated at all times. Don't swallow your sputum. Exercise regularly, and eat a well balanced diet, including the correct dosage of pancreatic enzymes.

## WHO TO CALL??

**Monday to Friday 8:30—5pm:**

CF nurses on **9076-3443** or **0418-596-938**

All other times call The Alfred switch board on 9076-2000 and ask to be put through the **Respiratory Reg** on call.

## HAEMOPTYSIS

### Haemoptysis in CF

People with cystic fibrosis may see blood in their sputum from time to time. Blood may appear as streaks in the sputum, blood stained sputum or fresh blood with coughing. The most common reason for blood vessels in the lungs to leak is the presence of inflammation and infection of the airways. Sudden increases in the amount of blood flow and pressure through the vessels can also cause blood to leak into the airways. Blood vessels are usually very efficient at repairing themselves and for this reason the bleeding normally stops within a 5-15 minute period and reduces over the next 24 - 48 hrs.

If you have haemoptysis for the first time or have had it in the past, the following information may help you.

#### Streaks or spots of blood in your sputum:

- Don't panic – remember mild haemoptysis affects more than half of adults with CF
- If you have been prescribed tranexamic acid, start taking 2 tablets three times per day or as instructed by your doctor.
- Reduce the force of coughing to gentle huffing and sputum clearing
- Reduce exercise intensity to gentle walking for 24 hrs or until bleeding has settled, whichever is longest.

Ring the clinic for advice about your antibiotics and physiotherapy including airway clearance, inhalations and exercise regime.

#### If you have a bigger bleed ie. 1/3 cup or more:

- Ring the CF Clinic (CF nurse coordinator or AIRmed Registrar) to let us know you have had a bleed.
- Come directly to the CF clinic (business hours) or Emergency Dept (after hours) for review. You may need to be admitted to hospital.

#### If you are concerned or it is a larger amount and doesn't stop within 5 minutes:

- Ring an ambulance on 000
- Lean onto the side you think is bleeding - to help keep the other lung clear.
- If you don't know which side is bleeding, remain upright.

**If you are taken to another hospital, it is important the doctor there contacts the CF Consultant at The Alfred as soon as possible.**

## OPTIONS FOR TREATMENT

You will be advised to come to hospital when, in the opinion of one of the CF doctors, your health has deteriorated or is likely to suffer if you do not receive more intensive treatment than you can manage at home. Depending on the severity of your illness, there are multiple options for care.

### WARD 5 EAST

5 East incorporates the CF centre of excellence, Asthma, Immunology and Respiratory medicine. Including lung transplantation. The ward is staffed by nurses who are experienced in the care of respiratory related illness, such as CF. Any person with CF who requires a hospital admission is prioritised to 5 East in an attempt to provide the best possible continuity of care.

### ALFRED CENTRE—MEDIHOTEL

Located is the relatively new Alfred Centre, the medi-hotel provides comfortable short term accommodation whilst completing investigations. The medi-hotel is staffed by general nursing staff. All patients will still receive care from the CF team. This facility is utilised if beds are unavailable on the ward, or if a 1 or 2 night stay only is required. This facility can be utilised when training to do your IV antibiotics at home.

### HOSPITAL IN THE HOME

The Alfred @ Home program is a hospital in the home program, which aims to provide individualised care to patients who require acute, home based nursing care. The goal of the program is to provide health care services for patients with acute illnesses that would otherwise be managed in the hospital setting. Alfred @ Home aims to meet the expectations of the patients, family, carer and treating medical unit, through the provision of specialised staff with skills in acute and community health care. The program offers a service 24 hours a day, 7 days a week, 365 days a year.

Talk to the nurse coordinators if you have any questions about this service.

## WARD 5 EAST FACILITIES

The ward has many facilities that make a long stay in hospital as comfortable as possible. If you are a member of Cystic

Fibrosis Victoria, you do not have to pay for the TV. All beds have a phone connection, that can be utilised for a fee. All single rooms have a small bar fridge for storing food and drinks. There are also two communal fridges where personal items can also be stored. Items in the communal fridge require an ID label.



We now have three lap tops and three USB sticks that are available for loan whilst you are an inpatient. There are also portable TV's with DVD / X-Box's attached ready for use.

With the assistance of one of our adult CF's, an art space program has been developed. Paints and crafts are available through our Occupational Therapist.



The ward has a well equipped gym that enables inpatients to improve their exercise capacity whilst in hospital. Amongst other things there is a treadmill, exercise bikes, fit balls, exercise mats, and a large flat screen TV available to utilised. The physiotherapist will show you through the gym on your first admission.

We have strict hygiene guidelines to prevent cross infection between patients.

## STAYING HYDRATED IN WARMER WEATHER (continued)

### **How much fluid is enough fluid?**

There is no single formula to work out exactly how much fluid each person with CF needs. Baseline requirements are around 35-45ml per kg body weight; but are higher in warmer or humid weather; with exercise and any other situations with excessive sweating (e.g. fevers). This means that for a 60kg person, the baseline fluid requirement is **2100-2700 ml (2.1 to 2.7 litres) per day**, but this could increase to more than 3000ml (3 litres) on some days. Except in special circumstances (e.g. very humid climates), it is unusual to need more than 4000ml/day (4 litres).

### **Tips for getting enough fluid**

**Limit** your intake of **caffeine-containing fluids (cola drinks, "energy drinks" [e.g. Red Bull, Mother], coffee, tea)** to the least amount you can – certainly no more than 1000ml/day (1 litre). Caffeine is a diuretic, so you pass more fluid in urine than you drank. If a large proportion of your fluid is caffeine-containing, you increase your risk of dehydration.

Set a target for your fluid intake and a plan for meeting your target. Don't get behind during the day. Thirst is not a good indicator of whether you need fluid, especially after exercise.

**Carry a water bottle with you: in the car, at work/school; keep one by your bed.** At home, fill a jug with water or cordial, so you will have some idea of how much you have drunk during the day.

### **Make sure you get enough salt**

Everyone's salt requirement is different. Salt can come from:

- The food we eat, especially processed and packaged foods
- Salt added in cooking and to food
- **Salty drinks, such as sports drinks (Gatorade is higher in salt than Powerade) and salt tablets**

Talk with your physiotherapist about exercise in the heat of summer and your dietitian about how much fluid and salt you need, and the best way for you to meet your needs. **Be aware that if your appetite drops, your salt intake from food may drop** considerably, so in these circumstances you need to get salt in other ways (e.g. salt tablets, sports drinks).

## STAYING HYDRATED IN WARMER WEATHER

The risk of dehydration and salt depletion increases markedly during the summer months. Getting enough fluid and salt all year round is important – but especially important in warmer weather.

### Dehydration and/or salt depletion can lead to:

- **Headaches**
- **Fatigue or lethargy, especially in the legs which can feel tired or “heavy”**
- **Thicker sputum which is harder to clear**
- **Constipation, sluggish bowel movements or even bowel obstruction**

Adequate intake of both fluid and salt is important for preventing all of the above problems, and helping you to feel at your best. Fluid is also important for maintaining good kidney function, and may help reduce the risk of kidney stones in people who have had them in the past.

### Indications that people with CF have diminished thirst response

Two exercise and dehydration studies were undertaken in the USA in the 90s involving children, adolescents and young adults with and without CF. Researchers set out to measure the amount of fluids subjects drank during vigorous exercise on hot days and their response to dehydration. Subjects ranged in age from 9- 20 years and participated in a number of vigorous exercise sessions in a gym environment in temperatures of 31 to 35°C. All were provided with freely available chilled fluids and encouraged to drink according to thirst. They found that subjects with CF drank much less and lost twice as much fluid compared to the controls. The studies concluded that subjects with CF greatly underestimate their fluid needs because of a diminished thirst response and undergo excessive dehydration during exercise in hot conditions.

## THE ALFRED

### FACILITIES:

- Café’s—located on the ground floor of the main ward block, and a smaller café on the ground floor in the Alfred Centre.
- Florist - near main entrance
- Pharmacy— for hospital scripts -located opposite the café
- Pharmacy — for gifts and other goods—located near the front entrance
- Hairdresser
- ATM’s— Westpac, Bendigo & Commonwealth within the post office
- Public telephones
- Taxi call telephone—at front entrance
- Chapel
- Post Office / General store.



### GETTING HERE:

BUS— #246 runs along Punt Road. 216, 219, 220 run along Commercial Road

TRAIN— To Prahran or South Yarra Station—and then walk / bus

TRAM— #72 runs along Commercial road and stops at the front of the hospital  
(Stop 26)

— # 5, 6, 16, 64, 67, 72—run along St Kilda Rd— get off at Commercial Rd  
(stop 25)

### CAR PARKING.

Under cover parking is available under the Alfred Centre. Disabled parking is scattered around the hospital. For more details see: [www.baysidehealth.org.au/patients\\_visitors/car\\_parking/](http://www.baysidehealth.org.au/patients_visitors/car_parking/).

Parking in the underground car park can be expensive if left for more than 24 hours. If possible, plan ahead and get someone to drop you off for an admission. There is a reduced rate for concession card holders. Reduced rate tickets are only given out in extreme circumstances.



## ADMISSIONS

There are several ways in which an admission can be arranged. The most common is a planned admission after being reviewed in clinic. In most cases admissions can be organised to fit in with your lifestyle.

If you become unwell at home, we suggest calling the nurse coordinators to discuss whether an early clinic review is needed, or whether an admission can be booked.

If you become unwell all of a sudden, and its after hours, we suggest you call the Respiratory registrar and present to the Alfred emergency department.

We encourage early intervention. Seeking advice early rather than later can shorten the length of stay in hospital. Especially in the case of a bowel blockage, early intervention can prevent surgery.

When you have called the coordinators to confirm your bed on the day of admission, you need to check in at Admissions, before coming up to the ward.

## WHAT TO BRING ???

- Physio equipment eg: flutter, PEP mask or Pari neb.
- Runners and gym appropriate clothing
- Your own doona or pillow - if desired.
- Enough medications to last you a day if your bed isn't ready: eg: creon, insulin, pain killers & pulmozyme
- Own feed pump—if on overnight feeds—including extension.
- Mobile phone / laptop / portable DVD player. (preferably with a lock )
- Air pump for nebulisers if you are going to the medi-hotel.

## SECURITY

We ask that you wear your ID bracelet at all times. If you wish to leave the ward for any reason, please discuss it with your nurse first. You will need to suggest a return time, and leave contact details. If you are away from the ward for an extended period of time, your bed may be declared vacant.

Valuables: We suggests you leave all precious valuables at home. If you have valuable items, a key can be obtained to lock your bedside drawers. **DO NOT LEAVE LAPTOP COMPUTERS OR VALUABLES UNATTENDED.**

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## PLANNING TRAVEL

Planning early will set you up for an enjoyable trip. There are a whole list of things to consider before booking your flights. Cystic Fibrosis Australia (CFA) provides advice on their website. Some things to consider are vaccinations, travel insurance that covers pre-existing conditions, adaptors for pumps, travel letters, medication supplies and an emergency plan if you happen to become unwell. Chat to the nurse coordinators for more information.

## SYMPTOM MANAGEMENT

**The following few pages discuss managing common CF complaints. Some of these may never happen to you, but it is always handy to know and recognise a problem should it arise.**

As an Adult Centre we understand you have been living and dealing with your CF for some time. As you are over 18, we encourage you to manage your own health. So if you have any questions about symptoms or your treatment, please feel free to ask.

We encourage you to call the nurse coordinators if you have any of the symptoms listed below and you are unsure about the treatment:

- Increase in sputum / change in colour
- Temperatures / night sweats
- Bowels not opened—with associated nausea / vomiting
- Sudden onset chest pain
- Haemoptysis (fresh blood in your sputum)

**Nurse coordinators:**

**Monday—Friday 8:30am—5pm Ph: 9076-3443**

**After hours—call Alfred switch: on 9076-2000**

**and ask for Respiratory Registrar**

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## SCRIPTS

The best opportunity to obtain scripts is while seeing your Consultant in clinic. They know you best, and will be able to adjust doses as necessary. They will also request the correct number of repeats. If you run out of medications, and you do not have a clinic appointment in the near future, you can go and see your GP. At last resort, scripts can be requested through Libby Francis—the clinic coordinator, but please allow a week for the script to arrive in the mail. As you can comprehend with 300 people in our care, a lot of people are requesting scripts. Please plan ahead, and don't leave it to the last minute to get your medications.

## TRAVEL REIMBURSEMENT

The Victorian patient transport assistance scheme (VPTAS) subsidises the travel and accommodation costs incurred by rural Victorians and an approved escort, who have no option but to travel a long distance to receive approved medical specialist services.

To be eligible you need to be a Victorian resident, and need to travel more than 100km for treatment.

More information: [www.health.vic.org.au/ruralhealth](http://www.health.vic.org.au/ruralhealth)

Application forms can be obtained from the nurses or social worker.

## SUPPLEMENTS

Many people with CF require oral supplements. Try to plan ahead and obtain supplies when you are in clinic. If you run out, please contact the Nutrition Department on 9076-3063.

## HELPFUL WEBSITES

[www.cysticfibrosis.org.au/](http://www.cysticfibrosis.org.au/)  
[www.alfred.org.au/](http://www.alfred.org.au/)  
[www.cfv.org.au](http://www.cfv.org.au) - Vic Branch  
[www.cysticfibrosis.ca](http://www.cysticfibrosis.ca) - Canadian site

## INFECTION CONTROL

Most adults with CF who are admitted to hospital have at least one type of micro-organism infecting or colonising in their lungs. The type/s that cause infection or colonisation vary widely between individuals and may change over time. There are a number of steps that we take and ask you to take, to minimise the risk of cross infection when you are in hospital. They are consistent with the guidelines developed by the Australian Cystic Fibrosis Association and include:

- Provision of accommodation in single rooms with separate facilities for those people with Burkholderia cepacia, MRSA, Stenotrophomonas Malto-philia, VRE and hVISA. (Facts sheets available ) Infection control has also agreed to isolate those who are pseudomonas free.
- When patients are required to share rooms, a thorough assessment of appropriateness of this allocation will be made by the medical and nursing staff.
- You will be provided with adequate supplies of tissues, sputum cups and rubbish bags in order to enable the safe disposal of sputum.
- Use of the gym facilities will be subject to strict controls.
- Sampling of sputum for identification of micro-organisms will occur immediately prior to or on admission to hospital, and at other times as a guide to treatment. You will be informed of any changes and any potential risk will be discussed with you.
- We are happy to answer any queries you may have about Infection Control or your sputum microbiology and treatment. Please ask the ward nursing staff, the CF doctors, coordinators or the Infection Control Practitioners.

We support CF Australia's view on preventing cross infection— by always keeping at least a metre distance between yourself and other people with CF. It is particularly important when in hospital to wash or cleanse your hands on a regular basis. Especially before eating, after airway clearance, and before and after using communal areas . Tubs of alcohol based gel are located in many places around the ward, and out patient areas.



## WARD ROUNDS

Ward rounds occur twice a week, typically on a Monday and a Thursday. A ward round is an opportunity for you and your CF team to discuss your progress and plan for getting home in the best shape possible. This ensures that you and your care team are clear about what is to happen during your stay and also alert them to issues that need to be followed up after you leave hospital. If you feel uncomfortable about participating in a ward round, please let us know.

## FACILITIES FOR FAMILIES

There are several family meeting rooms on the ward. With permission of the person with CF, partners and families are welcome to request meetings with medical and allied health team members.

In some circumstances, a family member or partner may wish to stay with you overnight. This is subject to hospital approval and can be organised by the nurse in charge. There are several hotels within close proximity to the Alfred. Cystic Fibrosis Victoria (CFV) can provide assistance with hospital-related accommodation costs.

## VISITING HOURS

There are no formal visiting hours, so provided there is no interruption to the treatment plan, your family and friends are welcome to see you at most times of the day. Please respect others need for quiet after 8pm.

## DISCHARGE TIMES

The preferred hospital discharge time is 10am. If you are not being picked up until later, you may be asked to vacate the room and sit in the TV room, to enable the bed to be prepared for another patient.

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## OUT PATIENTS

Our largest clinic occurs on a Thursday mornings between 8:30 and 12:30. We consider sputum micro-organisms when booking individuals into clinic. A few spots are available on other days of the week. The outpatient clinic is also located on the 5th floor, in 5B. On arrival to clinic you are to check in at the Reception, and you will then be collected for lung function testing. Once complete, you will see your Consultant, the Physiotherapist, and the Dietitian. On request, or as needed, the nurses, occupational therapist, social worker and psychologist can be available for discussions. Please allow a few hours for clinic. Parents / partners are welcome.

At the end of clinic please see the reception staff to check out, and receive your follow up appointment.

If you require a PORT flush, or any dressings, please notify the nurses when you arrive, to avoid delays at the end of clinic.

☀ If you are experiencing flu like symptoms, please let us know ASAP.

## WHAT TO BRING TO OUT PATIENTS

- A list of questions if you have any for the various team members.
- A list of your medications, including new scripts you require.
- Your pulmozyme freezer bag if you are needing a new supply.
- A summary of your recent blood sugar levels if you have diabetes.
- Bring any forms you need filling out by your specialist. Eg: travel insurance, sickness benefits, VPTAS and other centrelink paperwork.

**NO forms will be completed outside of a clinic appointments**

## RESEARCH

As a major cystic fibrosis treatment centre, we are constantly trying to look for better ways of managing the physical and emotional problems related to having CF. From time to time, we may ask you to participate in research that helps us gain a better understanding of the effects of treatments on your health and well being. We will attempt not to ask you to be involved with two studies at the same time. Participation is voluntary, and declining to be involved will not effect your care in any way.

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