



***A GUIDE TO GETTING THE MOST
FROM YOUR HOSPITAL STAY FOR
ADULTS WITH CYSTIC FIBROSIS***

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FOR ADULTS WITH
CYSTIC FIBROSIS**

Cystic Fibrosis Service

Department of Allergy, Immunology and Respiratory Medicine

The Alfred

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This booklet has been compiled by Felicity Finlayson, Coordinator, CF Service with input from nursing staff from Wards 5 East [Vanessa Edwards] and 4D (Medical Ambulatory Day Unit / Medihotel) [Kirsten Beerworth], Alfred @ Home [Lebe Malkoun], Infection Control, members of the medical, nursing and allied health CF specialist team and adults with cystic fibrosis who access the inpatient care options available at The Alfred.

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Introduction

Welcome to The Alfred

The Alfred is a large teaching hospital that provides health care services to 250,000 people every year. It has the widest range of adult specialist services of any major hospital in Victoria including trauma, burns, infectious Diseases/HIV, organ transplantation and cystic fibrosis. The Alfred is a leading research institution with close geographical and academic affiliations with the Baker and Burnett Institutes.



The first few adults with cystic fibrosis came from the Royal Children's Hospital to be cared for by Dr Margaret Smith in the late 1970's. Since then the specialist CF care team has grown to include three specialist physicians, a nurse coordinator, physiotherapists, dietitians, an occupational therapist, social worker, psychologist, clinic coordinator, liaison community support nurses and physiotherapist. From a few brave pioneers in those early days the number of people who access CF care today is closer to 250 with over 30 of those having had lung transplants. The Alfred is a designated CF Centre of Excellence and provides world class facilities for CF care.

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 cystic fibrosis 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 your feedback and comments and look forward to getting to know you and your family.

The aim of this booklet is to provide you with information to help make your experience of hospital-based treatment a positive one.

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 cystic fibrosis. When you are in hospital, you will meet a number of health care professionals who have different, but complementary, 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 one time, who may not be the doctor you usually see in the clinic. 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 eg. Endocrinologists and Diabetes Educators, Gastroenterologists, Radiologists, Continence Nurses, 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 other doctors and nurses.*
- *CF Resident Medical Officer: The doctor on the ward responsible for ensuring that you have the tests, medications and procedures you require. They also work closely with the Respiratory 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 admission to hospital.*
- *Respiratory Care Coordinators: The role of the Respiratory Care Coordinator is to ensure that your treatment is proceeding according to the plan worked out between you and your care team. He/she may discuss alternative treatment options and will ensure that all the necessary follow-up arrangements have been made for your discharge.*
- *Primary Nurse: A nurse assigned to you during your stay that is responsible for planning and implementing your hospital care with you. He/she is the person to whom you should first direct any questions about your day to day treatment plan.*

- *Resource Nurse: An experienced member of nursing staff responsible for patient care and coordination for the shift.*
- *Nurse Manager: Nurse responsible for effective operation of the ward and managing the nursing staff.*
- *Associate Nurses: Nurses who work with your primary nurse to administer your treatment, and provide you with information and support you need to make informed choices about your care while in hospital.*
- *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 prior to treatment.*
- *Dietitian: The dietitian will review your nutrition requirements and assist you to meet these while on the ward.*
- *Occupational Therapist: The OT may review your physical capacity and resources available to ensure you are able to pursue your chosen occupation / interests while receiving medical care.*
- *Social Worker: Assists you and your family 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 the 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 cystic fibrosis during your admission and after.*
- *Psychiatrist: Provides specialist opinion and treatment, where necessary, for mental health issues.*
- *Pharmacist: Reviews your medication and provides education to optimise the outcome of your treatment through their best use.*
- *Alfred @ Home Clinical Liaison Nurse: Responsible for assessing and organising the necessary supports for you when you are referred to the Alfred @ Home program for treatment outside hospital.*
- *RDNS CF Home Support Team: Can provide special CF nursing and physiotherapy monitoring and assistance to you at home.*
- *Ward Clerk: Is located at the reception desk and provides administrative support to the ward.*

The treatment goal.....

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

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, how quickly you respond to 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 practise, 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 plan.*

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 the agreed times for physiotherapy and gym sessions.*
- *To attend meetings, investigations and procedures at times specified by the service provider.*
- *To communicate any concerns, problems or difference of opinion to the relevant staff member, promptly.*

Options for Hospital-based care at The Alfred

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.

In order to minimise the interruption to your normal life caused by CF treatment, a number of alternative care settings are available.

- **Ward 5 East** incorporating CF Centre of Excellence – Asthma, Immunology and Respiratory Medicine as well as General Medicine.

This ward is staffed by nurses with broad general nursing experience as well as specialist experience in caring for people who are very unwell with conditions affecting the respiratory system, including cystic fibrosis. People who require a high degree of specialist medical and nursing care and support are admitted to this ward, as a priority.

- **Alfred Centre/2F** – Medical Ambulatory Day Unit (MADU) + Medihotel

This ward offers those who want to combine the support the hospital care environment provides to receive treatment, rest and recover from a chest infection with the flexibility to be able to attend work, study and/or social commitments.

It also allows rapid access to CF and other medical and allied health assessments, day procedures and inclusion into the Alfred@Home program.

MADU / Medihotel is a 15 bed unit which provides nursing care between the hours of 7am and 9pm seven days a week. However overnight the Medihotel is under the supervision of two Registered Nurses from 9pm to 7am.

The choice of MADU / Medihotel as location for you to receive your care will have been made by the CF team, in consultation with you, with your condition and treatment requirements in mind. This is continuously reassessed and a transfer to the ward can be arranged if necessary.

- **Facilities** - available on 5 East + in Alfred Centre

All beds have access to a TV and phone.

A centrally located refrigerator is available to store supplements and your own snacks. Food and drink in this fridge must be clearly labelled with your name and the date.



While this particular treatment option holds a degree of flexibility, patients in MADU are encouraged to maintain a level of responsibility for their own treatment.

During your stay on the ward you will have access to all the same facilities that you would if you were a patient on Ward 5 East. This includes the 5East gym. The CF team, allied health team, Coordinators and Doctors come to the ward most days to review your treatment and progress. You are free to ask the nurses to contact them, on your behalf, at any time.



■ **Alfred @ 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 patient, family, carer and treating medical unit, through the provision of specialised staff with skills in acute and community health care.

All patients on the program are considered inpatients of The Alfred and have access to all services and facilities. The introduction of a Clinical Pathway for people with CF experiencing a chest infection enables easy monitoring of progress by the visiting nurses. Each patient is allocated a Clinical Coordinator who monitors their care from admission to discharge and is the point of contact from the community to the CF team. The program offers a service 24 hours a day, 7 days a week, 365 days a year.

You may prefer one option over another or a combination. Feel free to discuss these with your doctor, Coordinators or your nurses.

What to bring with you when you come to hospital

OWN BSL MACHINE AND LOG-BOOK - so that you can maintain your own diabetes monitoring 'routine' whilst in hospital.

OWN FEED PUMPS - if you require feeds please bring in your pump, it is difficult to get these after hours, and it allows you to remain independent.

MOBILE PHONES - we do have phones by every bed, however we do allow mobile phones on the ward.

PILLOWS AND DOONAS - anything that you feel will improve your comfort while you stay with us.

PHYSIO EQUIPMENT - to continue your personal physio on the ward eg, flutters, PEP masks, gym wear.

Pulmozyme - with your Pari nebuliser

Alfred Centre/2F - MADU/ Medihotel

OWN MEDICATIONS - these can be replenished if necessary during your stay. We encourage our patients to remain self-medicating.

OWN AIR PUMPS - for your nebulised medications, otherwise we borrow from 5 East. We will keep you supplied with any nebs you need and are ordered.

Facilities available on-site at The Alfred;

Café with courtyard.

Florist

Pharmacy

ATM : Bank of Melbourne and Credit Union

Hairdresser

Public telephones

Taxi call telephone

Minimart - Post Office, Dry Cleaning and Tatts Agencies

Chapel



A few other things to note.....

Parking

Patient and visitor parking is available adjacent to The Alfred on the corner of Commercial and Punt Roads. There may be a wait to get in at 'peak times' so you may have to be patient or park in the 2 hour bays adjacent to the hospital. For patients staying in hospital or those visiting who are financially disadvantaged, discount parking is available. Bring your parking ticket / voucher with you to be authorised accordingly.

Admission

*Admission to hospital will usually be arranged by one of the doctors as a result of an assessment of your health, by your local GP, at an Alfred clinic visit or over the phone with the CF nurse coordinator. In most cases admission can be planned ahead to fit in with your lifestyle and allow the hospital to allocate you a bed. We encourage "early intervention". In other words, we encourage you to seek help if you are **becoming** unwell and what you are doing is not working, **before** you get very sick.*

If you are very unwell or need treatment straight away you may need to go to the Emergency Department (ED) or be admitted directly from the clinic.

When you are admitted to hospital from the ED, they will complete your admission documents down there. Admission to all other wards, including 5 East, is via the Admissions Desk on the ground floor, in transit lounge.

Security

Personal: We ask that you have an Alfred hospital ID band on your wrist or ankle during your hospital stay. You will be given a red band if you have any allergies or drug sensitivities.

If you wish to leave the ward for any reason for any period be sure to discuss it with the nurse caring for you on that shift. Whenever you leave the ward tell us when you will be back and provide us with a contact number for you. Failure to return by the agreed time may result in your bed being declared vacant.

All visitors are asked to identify themselves at the Ward Reception Desk or to the nurse looking after you.

Valuables: The bedside lockers and cupboards are lockable. Any items of value should be locked away when not in use. Any precious, non-essential items should not be brought in to hospital. We would suggest that you keep only enough money to buy any day to day needs.

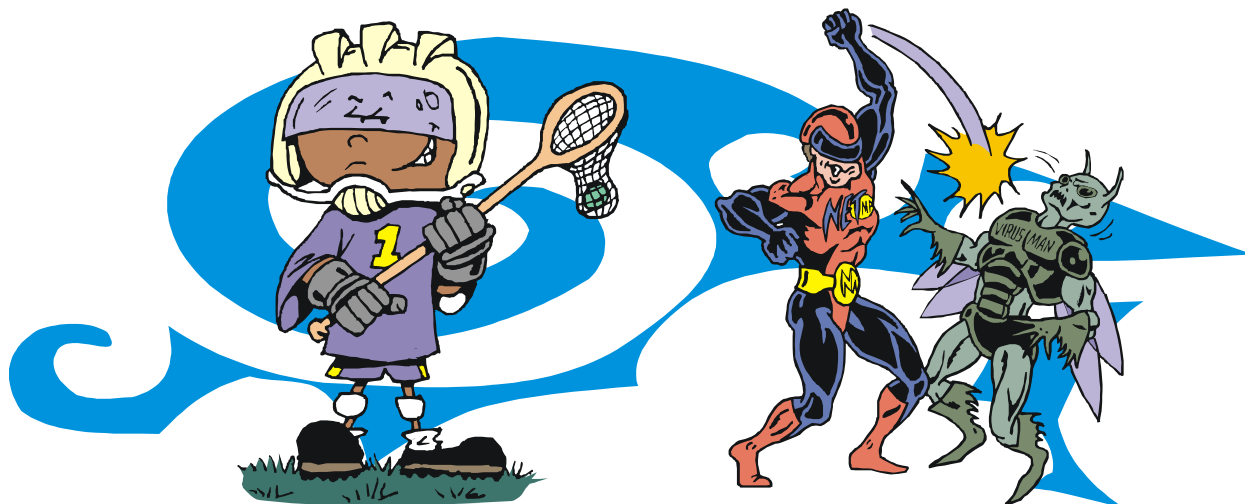
Massage Service

While in hospital you may like to receive a massage from the CF musculoskeletal physiotherapist.

Infection control

Most adults with CF who are admitted to hospital, have at least one type of micro-organism infecting or colonising 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 cepacia, MRSA*, maltophilia*, VRE* and hVISA* or other organisms identified by Infection Control as posing an infection risk to another person. (*Ask for a Fact Sheet.)*
- *When patients are required to share rooms, a thorough assessment of appropriateness of this allocation will be made by the medical and nursing staff on the ward in consultation with the Infection Control Staff.*
- *You will be provided with adequate supplies of tissues, sputum mugs and rubbish bags in order to enable the safe disposal of sputum.*
- *Hand basins with the appropriate cleansing/ disinfecting agents for handwashing will be located within convenient reach of rooms and the gymnasium.*
- *Use of the gym facilities will be subject to strict controls. (Please ask the ward staff for a copy of the Guidelines.)*
- *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 own sputum microbiology and treatment. Please ask the ward nursing staff, the CF doctors, coordinators or the Infection Control Practitioners.*



Ward Rounds

Ward Rounds are times during the week when the whole CF Team visits you. This usually occurs twice in any week, on a Monday and again on a Thursday. The purpose of the Ward round is to formulate your treatment plan with you for the next few days or the remainder of your stay. 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 Ward Rounds, please inform us to discuss an alternative.

Medications

When you come into hospital you will usually be prescribed most of the medications you take at home as well as those required to treat the specific problem for which you have been admitted. Any new medications should be explained to you. If you do not understand why you are being given a particular drug or if you notice unpleasant side effects please let us know.

You do not have to pay for the medications you are prescribed as part of your treatment while in hospital or on the Alfred @ Home program. You will have to pay for the medications you take home with you when you are discharged from hospital in the same way you pay for those prescribed to you in the clinic.

The ward Pharmacist is available to provide any information you require about your medications and discuss any complementary medicines you are taking.

Electrical items

Electrical items brought in for personal use must be checked and approved by the Engineering Dept staff before use. The Ward Clerk can arrange this for you. Extension cords and double adaptors cannot be brought in for safety reasons.

Computers

You may bring your laptop into the hospital for use on the ward. As with any item of value, you do so at your own risk. We would encourage you to lock it away whenever you are out of the room – even to go to the toilet! Access to a laptop (on permanent loan from Cystic Fibrosis Victoria) and a PC can be arranged through the Occupational Therapist or ward nursing staff. The hospital computers in the staff work areas are for the use of the staff to aid patient care and as a result there is tight security around “non-patient care” related access to the network. We would ask you not to request access to check email etc. unless the matter is urgent. If you do need to use a hospital computer it will be under the supervision of a member of medical, nursing or allied health staff.

Facilities for families

A family meeting room is located on the 5th Floor at the East end of the ward. Partners and families are welcome to request meetings with medical and other members of the team. However, these discussions will always be in the presence of or with full knowledge and consent of the person receiving treatment.

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 ward medical and nursing staff. There is a hotel directly opposite The Alfred, which is also very convenient. Assistance with hospital-related accommodation costs may be available from Cystic Fibrosis Victoria.

There are no formal visiting hours, so provided there is no interruption to the plan of treatment, your family and friends are welcome to see you at most times of the day and into the evening. Please respect others need for quiet after 8.00pm.

Lung Transplantation

The Alfred is one of the major centres for lung transplantation in Australia. Over 100 people with CF have had this procedure here. Information about lung transplantation is available to you and your families at any time. If you would like to speak with one of the Transplant team just let your doctor or nurse know you are interested in knowing more.

Research

As a major cystic fibrosis treatment centre, we are constantly trying to look for better ways of managing the physical and emotional problems caused by CF. From time to time, this may involve asking you to participate in research to help us gain a better understanding of the effects of treatments on your health and well-being. We try to ensure you are not being asked to participate in more than one study at a time. Any decision by you not to be part of a study will not effect your care in any way.

Discharge Time

When you are to be discharged, the preferred time is 10am. If you are not being picked until later than this we may ask you to vacate the room and sit in the waiting area so the bed is available if needed for another patient.

Kitchen and Laundry

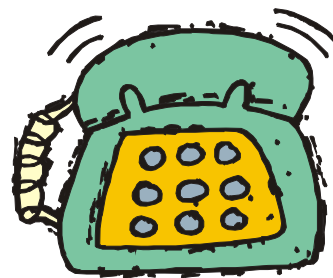
There is a kitchen with fridge, microwave and light refreshment supplies in the centre of Ward 5 East.

A washing machine and dryer are also available for patient use on the 5th Floor. BYO washing powder. Please report any breakdowns promptly.

Television

Cystic Fibrosis Victoria will cover the cost of TV hire for their members if you complete and fax through the application form as soon as you are admitted.

Useful contacts:



CF Service

<i>Head of CF Service</i>	9076 2315	
<i>Medical Staff</i>	9076 2315	
<i>General Enquiries</i>	9076 2315	
<i>Coordinator - CF nurse (Health Issues, Admission)</i>	9076 3443	<i>Pg: 4647</i>
<i>Clinic Coordinator (Appointments Scripts)</i>	9076 6960	<i>Pg: 4227</i>
<i>Senior Physiotherapist</i>	9076 2000	<i>Pg: 4601</i>
<i>Dietitian</i>	9076 3063	<i>Pg: 4122</i>
<i>Social Worker</i>	9076 3026	<i>Pg: 4432</i>
<i>Occupational Therapist</i>	9076 3526	<i>Pg: 4037</i>
<i>Psychologist</i>	9076 3805	<i>Pg: 4932</i>

Ward 5 East

<i>Respiratory Care Coordinator</i>	9076 2000	<i>Pg: 5081</i>
<i>Nurse Unit Manager</i>	9076 3651	

Alfred@Home

<i>Clinical Coordinator</i>	9076 6985	
<i>or via switch</i>	9076 2000	<i>Pg: 5596</i>

The Alfred

<i>Patient & Community Advocate</i>	9076 3028	
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FINALLY, on behalf of all of us here at The Alfred we hope you enjoy your stay with us.

