

MATER ADULT HOSPITAL CYSTIC FIBROSIS UNIT

INFORMATION BOOKLET

Changing hospitals can be a difficult and uncertain time. This package is designed to give you all the information you need to make the process as easy as possible.

The Adult Cystic Fibrosis Team is made up of nurses, doctors, physiotherapists, a dietician and social worker, in addition to further specialist referral services.

The goal of the Adult Cystic Fibrosis Unit is to provide each person with cystic fibrosis with an individualised approach to looking after their cystic fibrosis such that optimal health, well-being and lifestyle are achieved and maintained.



WELCOME to the Adult Cystic Fibrosis Unit at the Mater Hospital.

Our goal is to help you stay as well as possible so that you can get on with enjoying the important things in your life.

Changing hospitals and teams is a difficult time, and we hope to make the change as easy as possible for you. During the early period of change things can be frustrating for you as we learn how you like to do things, however we will always endeavour to individualise your management to best suit you and your life. Some of our ideas and approaches may be different from what you are used to - if our plans don't suit your life, please tell us and we will find a flexible solution.

We think the most effective way to manage your cystic fibrosis is through a partnership between you and the cystic fibrosis team. We understand that the treatments required as part of managing cystic fibrosis are intrusive and time-consuming, and we hope to individualise your treatment to suit you specifically.

Outpatients

Cystic Fibrosis clinics are held on the first and 3rd Monday afternoon of each month, between 2 pm and 430 pm.

They are held in the outpatients department on level 4 of the main Adults Hospital building. Appointments will be mailed to you, however you can arrange further appointments by contacting Sr Lisa Gilroy or any of the staff on ward 9b on 3840 8913.

We would ideally like to see you every 3 months in outpatients, even if you are well, however we will tailor appointment visits to suit your life.

The clinic appointment will generally involve a lung function test, weighing, sputum sample collection, and reviews with appropriate members of the team including doctor, nurse, physiotherapist, dietician and social worker.

It is important that you feel free to contact any member of the team between clinic visits if you need to.



Annual Reviews (“Roadworthys”)

During busy times at clinic or ward reviews, the fine detail related to the management of your cystic fibrosis may occasionally be overlooked. A periodic, full, “annual review” (sort of like a car “roadworthy”!) allows us to make sure that there are not little things that can be done to either improve your health or your quality of life. While these may not need to be done strictly every year for everyone, it is important that such a review is done every so often.

As well as reviews with the doctor, nurse, physiotherapists, dietician and social workers, a number of additional tests will be done as part of this review:

1. Blood tests
2. Bone density scan
3. Chest Xray
4. Sputum cultures
5. “Formal” lung function tests (in lung function laboratory)
6. 6 minute walk test
7. A food diary

These reviews will be booked so that you are seen on one of your scheduled outpatient visits (so that it doesn’t necessitate an extra hospital visit for you).

However, some of these extra tests will need to be performed up to 6 weeks prior to the review in outpatients so that results are available (e.g. blood tests, bone density scan), so you will be contacted before the review with bookings for these extra tests.

Hospital Admissions

Admissions to hospital will usually involve direct admissions to ward 9B.

There is a lot of work involved with organising and undertaking a hospital admission, both for yourselves and for hospital staff, so it is important to ensure it runs as smoothly as possible. If you are sick and needing extra treatment it is important that you let us know early rather than late as treatment at this stage is likely to result in much more rapid improvement. You should be thoughtful in your approach and expectations for admission. If you are unwell on a Monday, do not leave it to Friday afternoon to let the CF team know as this is a difficult time to arrange admissions, etc.

You can arrange for admissions to hospital for treatment by calling ward 9B on 3840 8913 and speaking to Sr Lisa Gilroy or other nursing staff, or by contacting one of the doctors directly (details follow).

It is very important that you come to Ward 9B for admission at the prearranged time, (or around lunch time if no time has been specified) as the organisation of an admission involves a lot of extra work for nursing and ward staff, doctors, etc, and presentations late in the day shift all of this work to a period when most staff would rather be on their way home!!

If you have work or other commitments then let us know and we will happily shift our arrangements to accommodate this.

If you require **urgent** medical attention (especially after-hours), please go directly to the emergency department and the adult cystic fibrosis team will be contacted.

Outpatient IV's

The Adult CF Unit has an active programme of home IV antibiotic therapy. Home IV antibiotic therapy is time-consuming and is not the best way for everyone to receive treatment. If you are interested in receiving home IV antibiotics please discuss with Sr Lisa Gilroy and the doctors.

“Ports” and “Buttons”

Ports and buttons are procedures that may be able to make your life more comfortable. “Ports” are devices that are semi-permanently placed under the skin in the upper arm or chest that allow direct access to the bloodstream without needing to have intravenous lines inserted whenever you need antibiotics.

“Buttons” are devices placed into the stomach through the abdomen that allow direct “feeding” into the stomach even when you are asleep, enabling you to gain weight and keep healthy if you are having trouble with your weight or nutrition normally.

If you have any questions regarding these, please contact one of the nurses or doctors to discuss this with you.

Lung Transplantation

Lung transplant is a service offered by the Heart and Lung Transplant Unit at the Prince Charles Hospital. The Adult Cystic Fibrosis Unit at the Mater Hospital has close links with Prince Charles’ Lung Transplant team and can arrange for consideration of this treatment option if it is appropriate. Transplant is considered for some people with cystic fibrosis who have poor quality of life and poor lung function. Although it is not generally a cure, it can significantly improve quality of life.

If you want to discuss this issue, please feel free to talk to one of your doctors at any time. While it may not be something that you need to consider at this point, discussion now may make future plans and discussions easier.

Research

There is no cure for CF yet, however improvements in treatments over the last 30 years have substantially improved the care we can offer patients with cystic fibrosis today. This has been the direct result of research activities.

The Adult CF Unit is committed to research activities aimed at improving the care and quality of life for cystic fibrosis patients. Many of the patients already being cared for here have been willing participants in a number of research trials and we always invite the participation of our patients in these activities. While this research may not directly improve your health or well-being, we hope that it may enable improvements in care for cystic fibrosis patients in the future.

Should you decide not to be involved in an invited research project, it will not in any way affect the quality of care that you receive.

OTHER ISSUES?

Should you have any questions at all regarding your cystic fibrosis, treatment or treatment options, or any issue at all, please feel free to contact any one of us.

THE ADULT CYSTIC FIBROSIS UNIT HEALTH CARE TEAM

Care Manager/ Coordinator

The care manager/ clinical nurse consultant coordinates your care “package” both as an inpatient and outpatient. Coordination of the various facets of your care will ensure that your total care needs are met, in an individualised manner. Your care manager will review you at outpatients, during admissions, and can be contacted during work hours at any other time on ward 9B.

Dietitian/ Nutritionist

Good nutrition is important for everyone, especially for patients with cystic fibrosis, due to increased nutritional requirements and reduced nutrient absorption. Extra energy, fat, protein, vitamins and minerals are required to help maintain a healthy weight and to assist in fighting infection. A dietician is available to assess your nutrition needs and provide nutrition support at outpatient clinics or on the wards. If you need to speak to a dietician at any other time please contact the nutrition and dietetic department.

Physiotherapists

The removal of sputum from the lungs ensures that the number of “bugs” within the airways is reduced, as well as removing those secretions that block the breathing tubes. This maintains your lung health by reducing inflammation (“redness” and “swelling”) in the breathing tubes and reducing the “bugs” in your lungs.

There are a number of different ways to clear the lungs, including exercise, and the Adult Cystic Fibrosis Unit physiotherapists are experts at determining the methods that work best for you, within your lifestyle.

The Adult cystic fibrosis unit physiotherapists will review you, and monitor your physiotherapy methods and progress, at outpatient visits and ward admissions. They can also be contacted at any other time that you may require their advice, in the Physiotherapy department.

Social worker

Cystic fibrosis places considerable emotional, financial and social burdens upon both cystic fibrosis individuals and their families. The Adult Cystic Fibrosis Unit social worker offers counselling and support services, practical advice for liaison with housing/ legal/ and council services, and facilitation of financial support services. The Adult Cystic Fibrosis Unit social worker will review you as needed during outpatient clinics and ward admissions, and can be contacted at any other times in the Social Work department.

Nursing staff

The nursing staff on ward 9B will care for you during hospital admissions, and are available for you to contact on the ward at any time. During admissions you will be allocated one nurse to care for you at each shift. They are experienced in the care of patients with cystic fibrosis and will often be your first port of call for telephone advice after-hours.

Doctors/ medical staff

The Adult Cystic Fibrosis Unit doctors are responsible for directing your therapy and ensuring you are on the most appropriate medications to maintain your health and well-being. The doctors caring for you comprise 2 consultant chest physicians, both with considerable experience in the management of adult cystic fibrosis, a senior registrar, and a resident medical officer. At outpatient reviews and during admissions you will be reviewed by 1 of the consultants, although you may see the senior registrar or resident first. The doctors are also able to arrange referrals to any other medical and surgical specialties as necessary, all with experience in cystic fibrosis. One of the doctors will always be available during working hours, and can always be contacted after hours if needed urgently. During working hours, the senior registrar can be contacted on ward 9B, and after hours 9B staff can contact one of the consultants.

HEALTH CARE TEAM CONTACT DETAILS

Doctors

Dr Simon Bowler	Consultant Chest Physician	Office – 3840 1178 A/ Hours – 3844 2219 Mobile – 0411 407996
Dr David Serisier	Consultant Chest Physician	Office – 3840 2407 A/ Hours– contact 9B (38408913) or switch (38408111) and ask to be put through to mobile
Dr Megan France	Senior Respiratory Registrar	3840 8913 or 3840 8111 (page 106)

Care Manager/ Coordinator and Clinical Nurse Consultant

Sr Lisa Gilroy	Respiratory CNC, Ward 9B	Phone 3840 8913 or 3840 8453
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Physiotherapists

Jenny Murphy	Senior Physiotherapist	Phone 3840 8787 (Page 676)
Michelle Wood	Senior Physiotherapist	Phone 3840 8787 (Page 316)

Dietitian/ Nutritionist

Sharyn Denmeade	Senior dietitian	Phone 3840 8585 (Page 674)
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Social Worker

Mek-el Cullinan	Senior Social Worker	Phone 3840 8785 (Page 738)
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OTHER IMPORTANT NUMBERS

Mater Adults Hospital Switchboard	3840 8111
Ward 9B	3840 8913
Lung function laboratory (Mr Andrew Coates)	3840 8146
Pharmacy	3840 8234
Outpatients Department	3840 8670