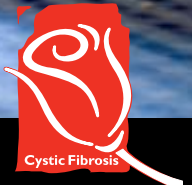


Moving On To Charlies

Information For Young Adults With Cystic Fibrosis



Acknowledgements

Cystic Fibrosis Western Australia

©2009 CF Transition Group Working Party
Sir Charles Gairdner Hospital

The CF Rose Logo is the copyright of Cystic Fibrosis Australia Ltd.
Its use in Western Australia is exclusively controlled and licensed by
the Cystic Fibrosis Association of WA Inc. All rights reserved.

AvpuScgh:3509-08

| Page | Contents |
|-------------|--|
| 2 | Hello and Welcome |
| 4 | What can I expect when I first visit SCGH? |
| 7 | What happens when I need hospital admission? |
| 8 | How will it be different at Charlies? |
| 10 | What do I do in an Emergency? |
| 11 | How do I get my Medications? |
| 12 | Home Treatment |
| 13 | Research |
| 14 | Meet the Team |
| 18 | CFWA |
| 20 | Parking |
| 20 | Public transport |
| 21 | Map of SCGH Site |



elcome to the Adult CF Centre at Sir Charles Gairdner Hospital (SCGH) also known as “Charlies”. The centre was established to provide specialist care for adults with Cystic Fibrosis.

Transition from the CF centre at Princess Margaret Hospital (PMH) to Sir Charles Gairdner CF centre can be an exciting time for young adults as they move on to the “adult world” and are no longer thought of as children. It can be a bit of relief to move on from the paediatric hospital for some young people. We understand it can be a difficult time too with challenges like meeting a new CF team, getting to know a new hospital and learning to care for yourself.

This brochure is one way we hope to make your transfer to “Charlies” a little easier. Members of our Adult CF Team here at Charlies will meet with you at least once at PMH and together we can agree on the right time for you to transfer your care to Charlies. The CF team here at the adult centre is committed to providing you with the best and most up to date treatment for Cystic Fibrosis and we make sure we adapt each person’s treatment to their own needs. We think it is very important that you have easy access to us whenever you need help. This brochure contains useful contact numbers to assist you, as well as tips on how to get here, where the CF unit is, and how to get around the clinics and the hospital.

The Cystic Fibrosis Association is conveniently located next to the hospital and can provide you with assistance. They are a useful source of advice and community support.

Please contact us if you need any further information. This brochure can also be found on the website www.tobearranged.com

**The CF Team
WA Adult CF Centre
Sir Charles Gairdner Hospital**



What can I expect when I first visit Charlies?

Cystic Fibrosis out-patient clinics are held in Department of Respiratory Medicine on the Ground Floor “B” block on Monday and Thursday afternoons. We will send you an appointment in the post.

If you are unable to attend clinic on that or any other day please inform the clinic staff by telephoning

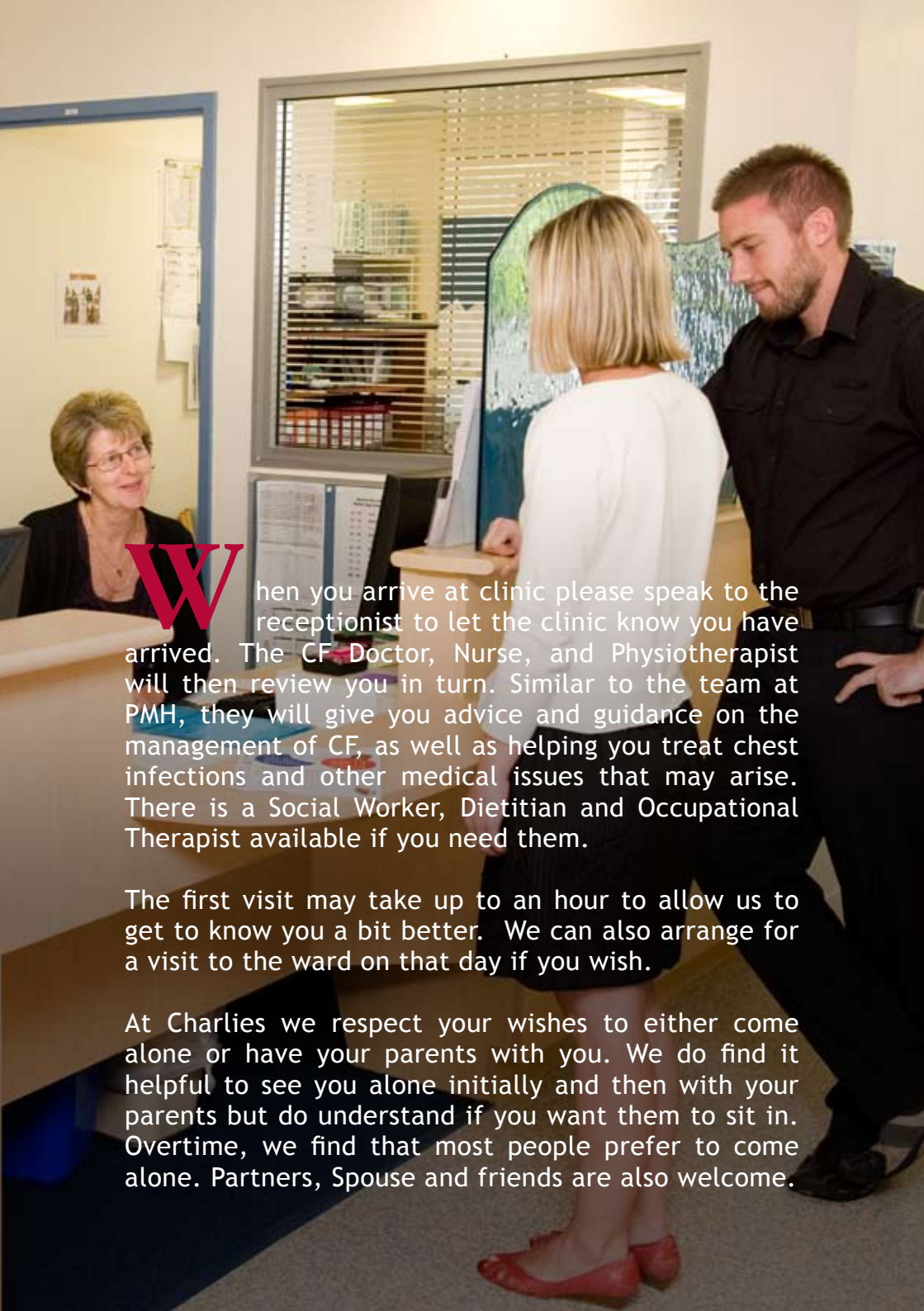
9346 1756.

← Western Australian Institute
for Medical Research Inc. (WAIMR)

← Department of Respiratory Medicine **B Block**

← Department of Otolaryngology **E Block**
ENT Surgery Clinic
Lions Hearing Clinic

← Cancer Centre



When you arrive at clinic please speak to the receptionist to let the clinic know you have arrived. The CF Doctor, Nurse, and Physiotherapist will then review you in turn. Similar to the team at PMH, they will give you advice and guidance on the management of CF, as well as helping you treat chest infections and other medical issues that may arise. There is a Social Worker, Dietitian and Occupational Therapist available if you need them.

The first visit may take up to an hour to allow us to get to know you a bit better. We can also arrange for a visit to the ward on that day if you wish.

At Charlies we respect your wishes to either come alone or have your parents with you. We do find it helpful to see you alone initially and then with your parents but do understand if you want them to sit in. Overtime, we find that most people prefer to come alone. Partners, Spouse and friends are also welcome.

What happens if I need hospital admission?

Sir Charles Gairdner Hospital has a respiratory ward (G54). This is on the 5th floor of G block (see our map on page 21). On this ward a specialist CF team will look after you. This team includes Doctors, Nurses, Physiotherapists, Dietician, Occupational Therapist, Social Worker and a Pharmacist. Young adults with CF will be admitted to G54 only and usually have a single room (this is due to infection-control policies).

G54 is a general respiratory ward and has specialist monitoring equipment. This can be quite noisy so it is fine if you choose to have the door to your room closed.

How will Charlies be different?

One of the most important general differences is that we expect you to be involved in making decisions about what treatment you use.

Differences in Outpatient Care

- Lung function is reported in litres rather than as a percentage.
- Older patients will be present in the clinic.
- Medications may be changed and be different to ones you used at PMH.

Please remember it is important that you take your Medicare Card with you every time you go to hospital or for a clinic appointment.

Differences in Inpatient Care

- Sir Charles Gairdner Hospital does not use the spring-fusor system on the ward. Our nurses will explain to you the different methods of IV administration.
- You will have access to exercise equipment in your room and won't exercise in a communal gym.
- Older people are also present on the ward.
- We have CF patient-only menus and snacks - eg cooked breakfast; coke and chips
- We have flexible treatment arrangements so you can go to work, college, uni etc.

The following facilities are also available

- DVD and TV on stand (Donated by Casey Dellacqua)
- Special rate on TV hire (soon to be Free)
- Fridge for your room

What do I do in an Emergency?

It is possible to be seen by someone in the team at Sir Charles Gairdner Hospital at short notice if you have a problem.

Office hours

(8am-6pm Monday-Friday) contact

Respiratory Outpatient Clinic on **9346 1756**
Sue Morey (CF Nurse Co-ordinator) **0410430352**

After hours

contact the on-call Respiratory Registrar or Ward G54 by telephoning the hospital switchboard on **9346 3333**.

Because patients with CF need specialist care, we recommend that you contact the Respiratory Registrar, Ward G54 or other CF team members instead of going direct to the Emergency Department at Sir Charles Gairdner Hospital. The emergency department is available for you of course if the matter is very urgent.

How do I get my Medications?

Out-patients:

Sir Charles Gairdner Hospital supplies any medicines you can obtain on the PBS (Pharmaceutical Benefits Scheme) just like your local chemist. There are some medicines you will need (and can only get) from the out-patient pharmacy. This is located on the ground floor of E block in the outpatient clinic (see the map on page 21). If the medicines are PBS items the prescription can be filled at your own chemist.

If you run out of medication before a clinic visit please inform either Sue Morey or the Outpatient Staff on the above numbers during office hours and we will arrange for a prescription or review.

In-patients:

If you are admitted to hospital for treatment, all your medication will be supplied for you, **with the exception of Pulmozyme and Vitamins**, which you will need to bring with you.



Home Treatment

Comprehensive Home Care (CHC packages)

As you may already know, Cystic Fibrosis Western Australia (CFWA) runs the Comprehensive Home Care program in conjunction with the PMH Hospital in the Home (HITH) program. The Comprehensive Home Care Services are a little different at SCGH and you can be referred for these services by the ward staff or CF clinic. You will be responsible for carrying out your own home IV antibiotic treatment and you will receive training from the ward nurses at SCGH. You will be reviewed twice a week by the CF Co-ordinator at clinic whilst having home IV anti-biotics. The CFWA nurse is available to visit at home. You would be eligible to Home Care Worker delivered airway clearance 3 times per week for two weeks.

For further information about this program ask the CF Co-ordinator (see page 16 for details).

Research

Sir Charles Gairdner Hospital is the major centre for adult respiratory research in Western Australia. Whilst you are a patient at Sir Charles Gairdner Hospital you may be asked from time to time if you would like to participate in CF related research. This is purely voluntary. You will also be asked to if you consent to your records being included in the Australasian CF Data Registry, just like at PMH. The information gathered for the Data Registry is confidential and to protect your identity and privacy your name and personal details are not recorded. If you are interested in getting involved with CF research feel free to let the CF team know.



The CF team can refer you to other services & facilities that you may require. Some of these are listed below

Diabetes & Endocrine

**Radiology And Vascular Intervention
For Infusaport And Picc Placement**

Pulmonary Physiology

Psychiatry

Gastroenterology/Hepatology

WA Genetic Counselling Services

Fertility Clinic

Obstetric & Gynaecology



Who are the Adult CF team & How do I contact them?

Doctors

| | | |
|--------------------|---------------|--|
| Gerard Ryan | Ph: 9346 3333 | Contact via page or mobile through switchboard |
| Martin Phillips | Ph: 9346 3333 | |
| Siobhain Mulrennan | Ph: 9346 3333 | |

Transplant and CF Co-ordinator

Sue Morey Ph: 9346 2318 Mob: 0410430352
sue.morey@health.wa.gov.au

Nurses (G54)

via Ward Clerk Ph: 9346 1654

Physiotherapist

| | |
|------------------|-------------|
| Jamie Wood | Pager: 4658 |
| Kathryn Crothers | Pager: 4236 |

Social Worker

Gemma Johnston Ph: 9346 4666 Pager: 4363

Occupational Therapist

Stuart Wilson Pager: 4231

Dietitian

Paul O'Neill Ph: 9346 2850 Pager: 4784

Pharmacist

Natalia Popowicz Ph: 9346 3333 Pager: 4242

Ward Clerk

Janice Roberts Ph: 9346 1654

Respiratory Medicine Outpatient Clinic Clerks

Pat Caulfield Ph: 9346 1756
Karen O'Neil
Narelle Sutherland

CFWA nurse

John Crofts Mobile: 0418194624

Email Office: info@cysticfibrosiswa.org

CFWA nurse: nurse@cysticfibrosiswa.org

CFWA

Cystic Fibrosis WA is pleased to contribute to this booklet to assist young people with CF and their families who are preparing for transition to health care at Sir Charles Gairdner Hospital. We recognise the importance of this transition process for all concerned, particularly for you as the young person taking this significant step forward.

Our organization is committed to providing effective community support to those affected by CF and to this end our role in your transition is to assist you to become familiar with the service and staff at Sir Charles Gairdner Hospital.

The CFWA Nurse will help you by taking you on a tour of the areas that you are likely to visit as part of your treatment plan and other areas that may be of interest to you such as the newsagent, Women's Auxiliary Shop, Coffee Shop, ATM's, and Public Telephones.

Parents and close relatives often need support during the transition process. Both CFWA and the CF Team at Charlies are available for support and advice if required

This booklet is designed so that it can be a useful reference, so please let us know if there is other information you wish to be included.

Cystic Fibrosis WA

Telephone

9346 7333

Monday to Friday: 9 am - 5 pm

Street Address

“The Niche”

11 Aberdare Road (Cnr Hospital Avenue)

Nedlands

Postal Address

Po Box 959

Nedlands WA 6909

Website

www.Cysticfibrosis.Org.Au/Wa



Parking

Public parking is available in car park No. 1 at \$0.60 per hour to a maximum of \$4.80 per day. Rows 5 and 6 are the closest to B block and rows 3 and 4 are closest to E block.

Note: as the car parks are often very busy, please allow ample time for parking. (See inside back page)

Public Transport

There are many buses that go past Sir Charles Gairdner Hospital. Transperth will help you plan your journey by calling 13 62 13 or visit the Transperth website www.transperth.wa.gov.au .

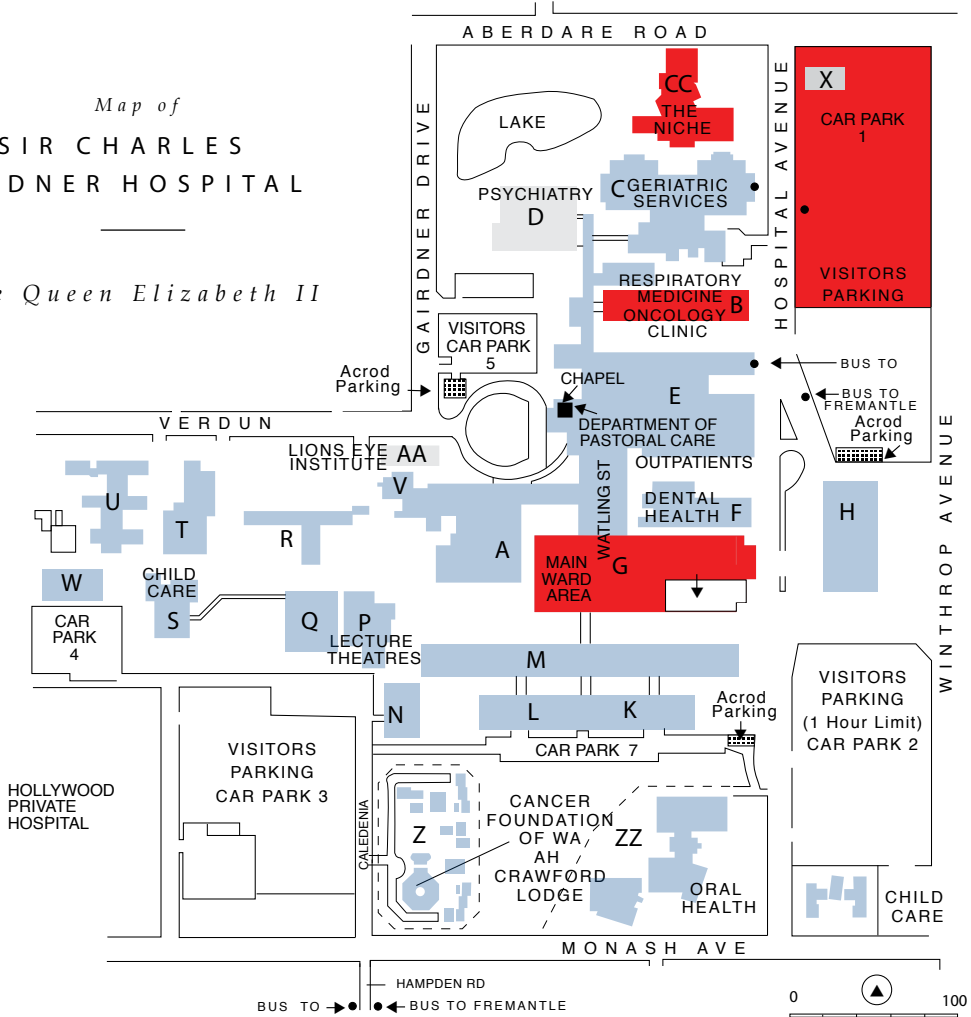
Below is a list of bus routes that stop on Hospital Avenue (that's the road along the front of the hospital):

98, 99, 97 (note: this bus stops at Subiaco train station), 103, 104, 32, 71, 72, 73, 75, 79, 23, 24, 25, 26.

Please note: Transperth has a Map Book which can be purchased from Perth Train Station, Wellington Street Bus Station, City Bus port, and the Plaza Arcade. The Transperth Map Book contains a range of helpful 'how to use information', with detailed maps of suburbs, streets and all the Transperth routes that operate in the area.

Map of
SIR CHARLES
GAIRDNER HOSPITAL

The Queen Elizabeth II



- Out-Patient Pharmacy: E Block (Ground floor)
- Respiratory Ward, G54: G Block (5th floor)
- Dept of Respiratory Medicine: B Block (Ground Floor)
- Public Visitors' Parking: Car Park 1 & 5
- Bus Stops:
- In front of C Block & E Block:
- outside (from South direction)
- opposite side of road (from North direction)

