



Government of **Western Australia**
North Metropolitan Health Service
Sir Charles Gairdner Osborne Park Health Care Group



Moving on to Charlies

Information for young adults with cystic fibrosis



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Welcome

Welcome to the WA Adult Cystic Fibrosis Centre at Sir Charles Gairdner Hospital (SCGH), also known as Charlies. The centre was established to provide specialist care for adults with cystic fibrosis (CF).

Transition from the CF centre at Perth Children's Hospital (PCH) to Charlies CF centre is an important milestone for young adults. It can be a relief to move on from the paediatric hospital for some young people. We understand it can be a difficult time too, with challenges such as 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 PCH and together we can agree on the right time for you to transfer your care to Charlies.

Our CF team 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 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 to find us, and how to get around the clinics and the hospital.

Cystic Fibrosis Western Australia (CFWA) is conveniently located next to the hospital and can provide assistance and support for you and your family. It is a useful source of advice and community support.

If you need further information, please call CFWA on ☎ (08) 6224 4100 or email info@cfwa.org.au.

What to expect on my first visit

Cystic fibrosis outpatient clinics are held in the Department of Respiratory Medicine on the Ground Floor, B Block, on Monday and Thursday afternoons and Friday mornings. We will send you an appointment time in the post.

If you are unable to attend your appointment it is important to inform the clinic staff by calling **(08) 6457 1756**. The clinic follows the hospital infection control policy and has set clinic days for specific infections.

When you arrive at the clinic, please let the receptionist know. The CF doctor, nurse, dietitian and physiotherapist will review you. Similar to the team at PCH, they will give advice and guidance on the management of CF, as well as help you treat chest infections and other medical issues that may arise.



Psychosocial support

The CF team at Charlies also includes a psychologist and a social worker. Your physical and mental health are integral to your wellbeing, and we know they can affect each other. Psychosocial support is available to patients experiencing life stressors and/or psychological difficulties. Examples of the things we can assist with include:

Psychological support for:

- Issues with mood, anxiety and depression
- Body image issues
- Trauma
- Parenting issues
- Family/relationship issues.

Social work support for:

- Case management and coordination with community services
- Advocating on your behalf
- Legal and Advanced Care planning
- Counselling and emotional support.



As part of the transfer process, the psychologist and social worker will each arrange an appointment to get to know more about you. If you decide down the track that you would like support from our psychologist or social worker, please ask one of your CF team to refer you.

Your first visit may take up to an hour to help us get to know you a bit better. We can also arrange for you to visit the inpatient ward the same day if you wish.

At Charlies, we respect your wishes to either come alone or bring your parents with you. We find it helpful to see you alone first, and then with your parents, but understand if you want them with you throughout the appointment. Over time, we find that most people prefer to come alone, but partners, spouses and friends are always welcome.



What happens if I need a hospital admission

Charlies has a respiratory ward (G54) on the 5th floor of G Block (refer to our map on page 18), where a specialist CF team will look after you. This team includes doctors, nurses, physiotherapists, a dietitian, a social worker and a pharmacist.

Young adults with CF will be admitted to G54 only, and usually have a single room due to infection-control policies. Like PCH, your admission to hospital can be organised as an urgent admission or we can book a future date.

If you feel sick and need an admission, you can contact the CF doctor or nurse practitioner at Charlies, who will organise for you to be seen and admitted to the ward (refer to page 14 for contact details).

G54 is a general respiratory ward for patients with a variety of lung problems, as well as patients with CF. This means patients have specialist monitoring equipment, which at times can be a little noisy. As such, it is entirely acceptable if you choose to have the door to your room closed.

Due to occupational health and safety and space issues, Ward G54 is not able to accommodate parents or partners within the rooms.





What's different at Charlies?

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

This is a natural progression as you become more independent.

Differences in outpatient care

- Lung function is reported in litres and as a percentage.
- Older patients who may look very sick will be in the clinic.
- Medications may be changed and be different to ones used at PCH.

Differences in inpatient care

- Charlies does not use the spring-fusor system on the ward. Our nurses will explain to you the different methods of IV administration used at Charlies.
- You will have access to exercise equipment in your room and in the physiotherapy gym.
- Older people may be on the ward, and we are likely to have patients on the ward with lung problems other than CF.
- We have specific menus just for our CF patients with dishes to choose from.
- We have flexible treatment arrangements so you can go to work, college, university, etc while receiving your treatment in hospital.

Please remember it is important that you take your Medicare card with you every time you go to hospital or for a clinic appointment and make sure that you notify us of any changes to your address or contact numbers.



What to do in an emergency

It is possible to be seen by someone in the team at Charlies at short notice if you have a problem. If you are sick and need to be seen urgently or at short notice, please use the contact details below to get in touch with the CF team at Charlies.

Office hours

Monday to Friday, 8.30am-5.00pm

Contact the Respiratory Outpatient Clinic on

📞 (08) 6457 1756

Sue Morey (CF Nurse Coordinator / CF Nurse Practitioner)

📞 mobile: 0410 430 352

If urgent, phone

📞 0410 430 352

After hours

Monday to Friday, 5.00pm to 8.30am and all day Saturday and Sunday. Contact the on-call respiratory registrar or Ward G54 by calling the hospital switchboard on

📞 (08) 6457 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 directly to the Emergency Department at Sir Charles Gairdner Hospital.

Naturally, the Emergency Department is available for you if the matter is extremely urgent or life threatening.

How do I get my medications?

Outpatients

There are some medicines you will need (and can only get) from the Outpatient Pharmacy. This is located on the ground floor of E Block in the Outpatient Clinic (refer to map on page 18). If the medicines are PBS items, you may be able to fill the prescription at your local chemist.

If you are likely to run out of medication before a clinic visit, please inform either Sue Morey or Outpatient staff on the listed contact numbers during office hours and we will arrange for a prescription or review.

Outpatient Pharmacy

 (08) 6457 2335

 scgh.pharmacyoutpatients@health.wa.gov.au

Inpatients

If you are admitted to hospital for treatment, all your medication will be supplied for you. You will need to bring in your own clinical trials medications, inhalers, Ivacaftor (Kalydeco®), Symdeko® or Trikafta® if you are on them, so we can continue to use your stock while you are on the ward.

If you have been started on intravenous (IV) antibiotics at home and then need to be admitted, please bring your supply of IV antibiotics with you as well.



Management of chest flare-ups

Home versus hospital treatment

Standard treatment of a chest exacerbation or “flare-up” of lung disease includes a combination of antibiotics, chest physiotherapy and nutritional support.

Milder flare-ups can be managed with outpatient oral and/or nebulised antibiotics. For moderate to significant flare-ups, you might need an admission to Charlies for IV antibiotics and more intensive support by the CF team to achieve the best outcome for your recovery.

In some cases, as guided by your CF specialty team, IV antibiotics can be done at home. You will receive detailed training from the ward and outpatient nurses at Charlies so you feel confident in administering your own IV antibiotics at home. You will be reviewed twice a week by the CF co-ordinator at the Outpatient Clinic while you are having home IV antibiotics.

You can be referred for CFWA home care services by the ward staff or from the CF clinic. A CFWA home-care worker can provide assistance with your home physiotherapy – the CF physiotherapist can arrange this for you.

For further information about this program, please ask our CF coordinator (refer to page 14 for details).

Research

Sir Charles Gairdner Hospital is the major centre for adult respiratory research in Western Australia.

The adult CF team has a close relationship with the Institute of Respiratory Health (IRH) and ongoing collaborations aim to both improve clinical care and to ensure patients have access to multicentre clinical trials. Cystic fibrosis clinical trials are performed at the IRH Clinical Trials Unit in the Harry Perkins Institute of Medical Research.

While you are a patient at Charlies, 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 if you consent to your records being included in the Australasian CF Data Registry, just like at PCH. The information gathered for the data registry is confidential. To protect your identify and privacy, your name and personal details are de-identified. If you are interested in getting involved with CF research, please feel free to let the CF team know.

The CF team can refer you to other services and facilities at Charlies you may require. Some of these are listed below:

- Diabetes and endocrine
- Radiology and vascular intervention for infusaport and PICC placement
- Pulmonary physiology and sleep medicine
- Psychiatry
- Gastroenterology/hepatology
- Ear, nose and throat
- WA Genetic Counselling Services (King Edward Memorial Hospital)
- Fertility clinics, obstetrics and gynaecology (King Edward Memorial Hospital)



Your CF team

CF Nurse Coordinator / CF Nurse Practitioner

Sue Morey  (08) 6457 2318  0410 430 352


 sue.morey@health.wa.gov.au

CF Outpatient Clinic clerks

Greame Harrison  (08) 6475 1756

Rhianne Suckling  (08) 6457 1756

Hanna Hastie  (08) 6457 1756

Komal Shah  (08) 6457 1756

Doctors

Siobhain Mulrennan  (08) 6457 3333

Doug Forrester  (08) 6457 3333

Physiotherapists

Tamara Thornton Pager: 4658

Emma Koenig Pager: 4658

Dietitian

Jordan Henderson Pager: 4784

Alice Baker Pager: 4784

Pharmacist

Sona Vekaria  cfpharmacist@health.wa.gov.au

 (08) 6457 2334

Psychologist

Annaliese Chapman  (08) 6457 7089

Social Worker

Remona Ghuman  (08) 6457 4666

G54 - Ward Clerk

Joanne Cocker  (08) 6457 1654

Cystic Fibrosis Western Australia (CFWA)

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

Our organisation is committed to providing community support to those affected by CF and our role in your transition is to offer you help in getting to know the hospital, the staff and the way things run at the CF centre at Charlies.

The CFWA team can assist by showing you around the hospital, the clinic and other areas such as the newsagency, coffee shop 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.

CFWA provide a home-care service to supply ongoing support in the home. This includes physiotherapy for airway clearance and exercise and cleaning support in times of need.

Mental health support is also available via CFWA.

CFWA subsidies include pharmaceutical and exercise, as well as hospital travel and parking support.

Cystic Fibrosis WA

Postal address

PO Box 959
Nedlands WA 6009

Street address

"The Niche"
Suite C/11 Aberdare Road
Nedlands WA 009

 (08) 6224 4100  info@cfwa.org.au

Opening hours Monday to Friday, 9am to 5pm

 www.cf.org.au/wa



Travelling to Charlies

There are several ways to get to the CF centre at Sir Charles Gairdner Hospital, which is located within the Queen Elizabeth II Medical Centre (QEII MC).

By car

- The main parking area is the Multi Deck Car Park, accessible from Winthrop Ave (see map, page 18) 24/7. The indoor, ground floor area of the Multi Deck contains the largest ACROD parking area at QEII MC (please note that normal parking fees do apply for these bays). You can call for transport from the carpark (by the Charlies Buggy) to the clinic on 📞0481 438 731.
- Parking fees are \$3.70 per hour with a maximum daily rate of \$25.90.
- You may be eligible for the Subsidised Parking Scheme if you meet the following criteria:
 - You have been admitted for symptom management for longer than one week
 - You require access to your car during your admission and by virtue of your illness are unable to use alternate forms of transport
 - You are approved by the treating team for leave from the ward.
 - If these apply to you, speak to your treating team about receiving \$6.05 per day subsidised parking tickets.

By public transport

- Transperth has a journey planning tool - www.transperth.wa.gov.au.
 - Bus stops along Hospital Avenue are located in front of the Oral Health Centre on Monash Avenue, outside G Block, and in front of C Block.
 - Timetables, SmartRiders and further information are available from the TravelSmart Junction, E Block, Ground Floor, QEII MC.
-  (08) 6457 4085 or  MCTravelsmart@health.wa.gov.au

Notes: _____

Important locations

Key



Outpatient Pharmacy:
E Block (Ground Floor)



Respiratory Ward, G 54:
G Block (5th Floor)



Respiratory Medicine
Outpatient Clinics:
B Block (Ground Floor)



Where to find us



Transport



Where to park



Scan the
QR code
for full
map







CONSUMER
REVIEWED



Acknowledgements

Cystic Fibrosis Western Australia

The Respiratory Health Network and Cystic Fibrosis Model of Care

This document can be made available in alternative formats on request.



Sir Charles Gairdner Hospital is proud to be a smoke-free site.

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