

Welcome to the Adult Cystic Fibrosis Service

Adult Cystic Fibrosis Service

Information for Patients

Produced: April 2022

Review: April 2025

Leaflet number: 1293 Version: 1

How to find us

The Cystic Fibrosis (CF) nurses and the Service Coordinator are based in the CF office at Glenfield Hospital. As you enter the East entrance you will see a lift and a stairway on the right which takes you to the lower floor. Please take the lift or the stairs to the lower floor. The CF Office is on the right as you enter the lower floor.

If you are being seen by one of the CF nurses, we ask that you knock on the CF office door so we can take you to the treatment room that is based on Ward 15.

The **Cystic Fibrosis Unit** is based on Ward 16 at Glenfield Hospital. You are best to access the hospital via the East entrance where you will find Ward 16 along the corridor on the left.

The **Clinical Decisions Unit** (CDU) is near the South Entrance.

Outpatients appointments

Your outpatient appointments will either be by telephone, online by video link or at the hospitals outpatient department. You will be told by letter/text message which type of consultation you will be having.

Face-to-face outpatients appointments are held in **Clinic A**. As you enter the hospital's main entrance turn left at the reception and continue round where you will find Clinic A straight ahead on the left.

- **General CF Clinics** are held on Thursday mornings between 09:00 to 12:30.
- **Difficult Bugs Clinics** are held on the 4th Friday of the month in the morning between 09:00 to 12:30.
- **Diabetic Clinics** are held on the 4th Friday of the month in the afternoon between 2:00 pm to 4:30pm

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

It is well known that close contact between people with CF in enclosed environments such as clinics can be a source of cross-infection. To prevent any cross-infection you will be shown into a separate clinic room where the whole of your clinic appointment will take place. CF team members will then see you separately in your room. On each clinic visit, a number of routine tests will be done, these will include weight, height, sputum samples and lung function. Some visits will include blood tests and chest X-rays.

Please make sure that we have your correct phone number as you will receive a text message reminding you of your appointment. This message also allows you to cancel your appointment. If you are not able to attend your outpatient appointment please let us know. Use the 2-way text messaging service or contact the Service Coordinator (**0116 250 2699**) as this appointment could be given to someone else. It is important that you attend your appointment as we are often booked up to 3 months in advance with little space to change appointments.

Telephone and video consultations: You will be told if your consultation is by telephone or video link. We ask that you tell the Service Coordinator if your email address or contact phone number changes. To help assess your clinical needs, we ask that you:

- have an up-to-date weight.
- if you have a Spirobank spirometer, to email the results to **AdultCysticFibrosisS@uhl-tr.nhs.uk** the day before the consultation.
- if you use a FreeStyle Libre flash glucose monitor and only use the libre reader, please make sure that it is downloaded for us to view.
- have an up to date list of your medication.

Appointments outside of clinic times (nurse lead appointments)

On some occasions, it may be necessary for you to be seen and assessed outside of clinic times. At these times, arrangements will be made for you to come to the CF treatment room where you will be seen by one of our CF nurses. This is called a ward attender appointment.

Home visits

Home visits are available and can be arranged by contacting the CF nurses. The CF nurse may also want to visit you at home, this could be for blood tests, spirometry, hospital discharge follow-ups or to assess your general health in your home environment.

Having intravenous antibiotics at home

There are strict guidelines in place to be able to give (administer) your intravenous antibiotics at home. If you have not given your intravenous antibiotics before and would like to do so, you need to stay in hospital for the first few days. This is so we can teach you how to give your antibiotics safely. The ward nurses and the CF nurses will watch you mix and administer your intravenous antibiotics and will assess if you are competent to do this at home.

To ensure safety and monitoring throughout the course, you will need to sign a contract to ensure you:

- will attend for blood tests.
- complete your course of intravenous antibiotics.
- attend ward attender appointments as needed.

If you do not follow the contract this may result in you not being able to give your intravenous antibiotics at home.

Prescriptions

The CF nurses are not able to prescribe routine medication that is regularly given to you by your GP, so it is important that you attend your medication review with your GP to allow:

- Your GP to have a full history of what medication you are taking.
- So that you are able to get your medicines on repeat prescription
- It allows you to be able to manage your prescriptions easier.

The CF nurses will be able to prescribe inhaled antibiotics, DNase, back up antibiotics and some oral medications. Please try not to run out of your medication as prescriptions requests will only be dealt with on a **Tuesday morning** and a **Thursday afternoon**. Please make arrangements with the CF team about collection/ delivery of your medication.

TrustMed pharmacy is located near the hospitals main entrance. As you enter the main entrance continue past the shop on right, you will see a cash machine on the left. Turn left here and continue round where you will see the TrustMed pharmacy on your right. **Opening hours are 9:00am to 6:00pm Monday to Friday.**

What to do if you are unwell?

There are several options if you feel unwell:

- If you feel unwell and have symptoms related to your CF please contact one of the CF nurses or ring the main office (**0116 250 2699**) to arrange a ward attender appointment. This may not be on the same day. You will be reviewed and assessed by one of our CF nurses.
- If you feel you need to be admitted into hospital please contact one of the CF nurses.
- If you feel you need to be seen by a consultant please contact the Service Co-ordinator to enquire if there are any clinic appointments available for that week. If there are no appointments available you will be offered a ward attender appointment with one of the CF nurses.
- If you are unwell and need admission at the weekend or outside of the hours worked by the CF nurses please ring Ward 16 (0116 258 3995) and speak to the nurse in charge.

What do the different staff in the service do?

Our team consists of many different medical staff who will be involved in your treatment and care. A description of the different members of our team and what they do are given below.

Specialist Consultants:

We have 3 consultant physicians that specialise in cystic fibrosis (CF) as well as specialist registrars in the team.

Cystic Fibrosis Service Co-ordinator:

The Service Co-ordinator manages all the CF clinics. They will be your first point of contact when you arrive for your clinic appointment and will check that your contact details are correct. If you have queries about your appointments or have general enquiries please contact the Service Co-ordinator using the details on the last page.

Specialist Nurses:

There are 3 CF specialist nurses within the team. The CF specialist nurses are available to provide advice and support with your nursing care, such as having antibiotics at home, inserting intravenous lines or any other problems you may have related to your CF. Home visits are available and can be arranged with our CF nurses. There are also times the CF nurse may want to visit you at home.

If you need help completing your Personal Independent Payment (PIP) forms the team will assist you with this and can attend assessments if you wish. If you become unwell and require treatment, please contact one of the specialist nurses using the contact details on the last page or the main office Monday to Friday.

Specialist Physiotherapists

There are 4 physiotherapists working within the CF team. The team will review your physiotherapy:

- If you are admitted to hospital
- If you start home intravenous antibiotics
- If you need a refresher or reassessment of your physio techniques
- If you need a home visit for a specific problem

The physiotherapists also provide out-patient supervised gym sessions to help you gain confidence in exercising and one-off gym visits in the community to help you set up/refresh a gym programme.

Advanced Specialist Pharmacist

The Advanced Specialist Pharmacist will review your medication with you at your outpatient clinic appointment and if you are admitted into hospital.

They will talk to you and help you with:

- Making sure your medication list is up to date
- Arranging supplies of medication which are from the hospital only.
- Education and counselling to make sure you can take your medicines safely and well.
- Any problem you may have with taking your medicines including side effects, remembering to take them, supply problems and medication regimes
- Support with making a plan to improve taking your medicines if needed

The Advanced Specialist Pharmacist can be contacted via the CF team using the details on the last page.

Clinical Psychologist

A clinical psychologist works with people who may be having difficulties in their life and would like some additional support. They aim to meet with everyone who attends the service so that they can get to know you and discuss how you are. This can help identify if there are any issues that you may need help with and also prevent any problems from building up.

As part of your annual review, the clinical psychologist will ask you to complete a questionnaire . This is to review how you have been over the past year. It allows you the chance to let them know if there is anything that you have been struggling with and would like some help to overcome any problems you may have. It is not uncommon for people to struggle to manage at times and seeing a psychologist does not mean that there is anything wrong, it simply means that you may need some more support. If you feel that you would benefit from seeing please speak to one of the CF team.

Specialist Diabetes Nurse

The specialist diabetes nurse is there to help you with any concerns you may have about managing your diabetes. This may include dietary advice, insulin management or the start of treatment. They aim to see patients with diabetes in the CF clinic or in the diabetic clinic. They also support and monitor those patients who use the FreeStyle Libre flash glucose monitoring system. The specialist diabetes nurse can be contacted using the details on the last page.

Specialist Dietitian

Good nutrition and a healthy body weight have been linked with better lung function and less frequent chest infections for people with cystic fibrosis. The specialist dietitian can guide, support and encourage you to get the best possible food and nutrition by giving:

- dietary advice and support in the form of individual assessment and treatment plans.
- advice and developing care plans for supplementary nutrition support such as supplement drinks and tube feeding.
- guidance and support on pancreatic enzyme therapy, fat soluble vitamins, salt supplementation and bone health.
- any extra help and support you need with other conditions such as cystic fibrosis related diabetes.

The specialist dietician can be contacted via the CF team using the details on the last page.

Consultant Microbiologist

The Consultant Microbiologist works alongside the CF team. They advise the CF team on the most appropriate antibiotics and anti-fungal medications which makes sure treatment plans are personal.

Contact details

Consultants

Dr Simon Range
Dr Chandra Ohri
Dr Andrew Clayton

Contact via the Cystic Fibrosis team

Main Office and email address

0116 250 2699
AdultCysticFibrosisS@uhl-tr.nhs.uk

Cystic Fibrosis Service Co-ordinator

Julia Kowal (8am to 6pm Monday, Tuesday and Thursday) Julia.Kowal@uhl-tr.nhs.uk

Specialist Nurses

(8am to 5pm Monday to Friday)

0116 250 2699

Berni Donaghy
Darren Tature
Paula Tinley

07908324629
07971744776
07950888483

Specialist Dietician

Lydia Stevens (9am to 5pm Monday, Tuesday, Thursday, Friday)

Contact via the Cystic Fibrosis team

Specialist Physiotherapist

Nicky Mills (8am to 4:30pm Monday to Friday)

07950882646

Advanced Specialist Pharmacist

Jessica Gadsby (9am to 4pm Monday, Wednesday, Thursday, Friday Morning 9am to 1pm)

Contact via the Cystic Fibrosis team

Clinical Psychologist

Nicola Buccheri

Referrals via the Cystic Fibrosis

Diabetic Nurse

Danielle Bruce

07432546428

Diabetic Helpline 0116 258 4919 or
via the Cystic Fibrosis Team

Ward 16

Sister Donna Suffolk

0116 258 3995

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk