

# Welcome to the Adult Cystic Fibrosis Service

## Adult Cystic Fibrosis Service

Information for Patients

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### How to find us?

- The **Adult Cystic Fibrosis office** is located at Glenfield Hospital. This is where the Cystic Fibrosis (CF) nurses are based. To get to this office you need to enter from 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 here to see a CF nurse then please knock on the CF office door. They will then take you to the treatment room on Ward 15.
- The **Cystic Fibrosis Unit** is on Ward 16 at Glenfield Hospital. You need to enter through the East entrance. You will find Ward 16 along the corridor on the left.
- The **Clinical Decisions Unit (CDU)** is at Glenfield Hospital. It is near the South Entrance.

### Outpatients appointments

Your hospital outpatient appointment will be in the hospital's outpatient department. In some cases, the CF team may decide that the appointment can be carried out online by video link.

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

- **General CF Clinics:** Thursday and some Friday mornings between 9am to 12:30pm (midday).
- **Difficult Bugs Clinics:** Every 3 months, on the 4th Friday of that month, between 9am to 12:30pm (midday).
- **Diabetic Clinics:** 4th Friday of the month between 9am to 12:30pm (midday).

Health information and support is available at [www.nhs.uk](http://www.nhs.uk)  
or call 111 for non-emergency medical advice

Visit [www.uhleicester.nhs.uk](http://www.uhleicester.nhs.uk) for maps and information about visiting Leicester's Hospitals  
To give feedback about this information sheet, contact [uhl-tr.informationforpatientsmailbox@nhs.net](mailto:uhl-tr.informationforpatientsmailbox@nhs.net)

Close contact between people with CF in small spaces, such as clinics, can increase the risk of cross-infection. To reduce this risk, we will take you to a separate clinic room for your appointment. Members of the CF team will see you individually in your room. During each visit we carry out a number of routine tests. These may include checking your weight, height and blood pressure, taking sputum samples and doing lung function tests. In some visits you may also need to have blood tests and chest X-rays.

Please make sure we have your correct phone number. This is because we will send a text message to remind you about your appointment. The message will also let you cancel your appointment if needed. Please let us know as soon as possible if you cannot attend your appointment. You can cancel using the 2-way text messaging service or by contacting the Service Coordinator on **0116 250 2699**. We can then offer your appointment to another patient. It is important that you attend your appointment. Clinics are often fully booked up to 3 months in advance. It can be difficult to change appointments.

**Video consultations:** Please let the Service Coordinator / nurses know if your email address or contact phone number changes. For video consultation we ask that you:

- have an up-to-date weight.
- if you have a Spirobank spirometer, to email the results to **uhl-tr.adultcysticfibrosisservice@nhs.net** the day before the consultation.
- have an up to date list of your medication.

This information helps us assess your clinical needs.

## Appointments outside of clinic times (nurse lead appointments)

Sometimes, we may need to see and assess you outside of clinic times. We will make arrangements for you to come to the CF treatment room. One of the CF nurses will see you. If needed a physiotherapist may also see you. This is called a ward attender appointment.

## Home visits

Home visits are available. You can arrange this by contacting the CF nurses or physiotherapy team.

The CF nurse may also want to visit you at home. This could be for:

- blood tests,
- spirometry,
- hospital discharge follow-ups,
- to assess your general health in your home.

The physiotherapy team may also carry out home visits. This may include support with:

- airway clearance,
- symptom management,
- treatment adherence,
- breathing pattern management,
- help with exercise programmes.

## Having intravenous antibiotics at home

There are strict guidelines for patients who wish to give themselves intravenous antibiotics at home. If you would like to do this you will need to stay in hospital for the first few days. This is so we can teach you how to give the antibiotics safely. This is for those who have not given themselves intravenous antibiotics at home before, those who are new to the service and those who have not had intravenous antibiotics for over a year.

Ward nurses and CF nurses will show you how to prepare and give (administer) your intravenous antibiotics. They will watch you doing this. They will assess if you can continue the treatment safely at home.

To make sure you stay safe and are properly monitored during your treatment, you will need to sign an agreement confirming that you will:

- attend for blood tests
- finish the full course of intravenous antibiotics
- attend ward attender appointments if needed

If these conditions are not followed, you may not be able to continue administering intravenous antibiotics at home.

## Prescriptions

The CF nurses cannot prescribe routine medication that is regularly prescribed by your GP. It is important that you attend your medication review with your GP to:

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

The CF nurses will be able to prescribe inhaled antibiotics, DNase and back up antibiotics

Please try not to run out of your medication. Prescription requests are only processed on Tuesday mornings and Thursday afternoons. Please contact the CF team to arrange collection or delivery of your medication.

Storage space in the pharmacy department is limited, so prescriptions can only be held for 14 days. If your prescription is not collected within this time, it will be returned to the pharmacy.

TrustMed Pharmacy is located near the hospital's main entrance. When you enter through the main entrance, walk past the shop on the right. You will see a cash machine on the left, turn left at this point. Continue walking and you will find TrustMed Pharmacy on your right.

**Opening hours are 9am to 6pm Monday to Friday.**

## What to do if you are unwell?

- **If you have symptoms related to your CF:** Contact the CF nurses or call the main office (0116 250 2699) to arrange a ward attender appointment. This appointment may not always be on the same day. A CF nurse will review and assess you. A physiotherapists may also see you if needed.
- **If you feel you need to be admitted into hospital:** Contact a CF nurses.
- **If you feel you need to be seen by a consultant:** Contact the Service Co-ordinator or CF nurses to see if there are any clinic appointments available for that week. If there are no appointments available you may be offered a ward attender appointment with one of the CF nurses.
- **If you need admission at the weekend or outside working hours:** Call Ward 16 (0116 258 3995) and speak to the nurse in charge or call the **NHS 111** service.

## What do the different staff in the service do?

Our team has many different medical staff who will be part of your treatment and care. Here are the different members of our team:

### Specialist consultants:

We have 4 consultant doctors who specialise in CF. There are also specialist doctors in training who work as part of the team.

### Cystic Fibrosis Service Co-ordinator:

You will often meet the Service Co-ordinator first when you arrive for your clinic appointment. They will check that your contact details are correct. Contact the Service Co-ordinator if you have any questions about your appointment or other queries. You can find the contact details on page 6.

### Specialist nurses:

There are 3 CF specialist nurses in the team. The CF specialist nurses are available to give advice and support with your nursing care. This may include help with having antibiotics at home, inserting intravenous lines or help with any other CF-related problem. The CF nurses can also arrange home visits if needed.

If you need help completing your Personal Independent Payment (PIP) forms the team will help you with this. They can attend assessments if you wish. Please contact the specialist nurses if you become unwell and need treatment. You can find the contact details on page 7 or visit 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 can also help with out-patient supervised gym sessions to help you build confidence in exercising. They can arrange one-off gym visits in the community to help you set up or 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 effectively.
- 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.

You can contact the advanced specialist pharmacist through the CF team. You can find the contact details on page 7.

## Clinical psychologist

A clinical psychologist works with people who may be having difficulties in their life and would like some support. They aim to meet with everyone who attends the service. This is so that they can get to know you and talk about how you are. This can help to find any problems that you may need help with. It can also stop any problems building up. This can help find any problems you may need support with stop any problems 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 lets you have 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. It is normal for people to struggle to manage at times. 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 this 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 flash / continuous glucose monitoring devices. Contact the specialist diabetes nurse using the details on the last page.

## Specialist dietitian

Good nutrition and a healthy body weight have been linked with better lung function. It is also linked with 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.

Contact the specialist dietitian through the CF team using the details on page 7.

## Consultant microbiologist

The consultant microbiologist works closely with the CF team. They give expert advice on the best antibiotics and antifungal medications. This is to make sure treatment plans are personalised and effective.

## Contact details

**Main Office and email address:** 0116 250 2699 / [uhl-tr.adultcysticfibrosisservice@nhs.net](mailto:uhl-tr.adultcysticfibrosisservice@nhs.net)

**Consultants:** (contact them through the Cystic Fibrosis team)

- Dr Chandra Ohri
- Dr Simon Range
- Dr Andrew Clayton
- Dr Eleni Avraam

**Cystic Fibrosis Service Co-ordinator:** 0116 250 2699 / 0116 258 3257

Eleanor Wells



**Specialist Nurses:** 0116 250 2699 (Monday to Friday, 8am to 4pm )

Berni Donaghy	0790 832 4629
Rebekah Mayer	0748 313 4557
Paula Tinley	0795 088 8483

**Specialist Dietitian:** (contact them through the Cystic Fibrosis team)

Jenny Briafield

**Specialist Physiotherapist:** 0795 088 2646 (Monday to Friday, 8am to 4:30pm)

Nicky Mills  
Enfys Jones

**Advanced Specialist Pharmacist:** (contact them through the Cystic Fibrosis team)

Jessica Gadsby

**Clinical Psychologist:** Referrals through the Cystic Fibrosis

Nicola Buccheri

**Diabetic Nurse:** (contact them through the Cystic Fibrosis team)

Tashana Williams  
Diabetic Helpline: 0116 258 4919

**Ward 16:** 0116 258 3995

Sister Donna Suffolk

**Trustmed Pharmacy:** 0116 235 5474

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 અસ્ય 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 [uhl-tr.equalitymailbox@nhs.net](mailto:uhl-tr.equalitymailbox@nhs.net)