

Transition in cystic fibrosis (CF)



Who is this leaflet for?

This leaflet is aimed at adolescents (teenagers) with cystic fibrosis and their families. It explains how and when you will transfer to the adult services the hospital provides.

What happens when I transfer?

Your transition from paediatric to adult care should be a gradual, planned process. During your visits to the adolescent clinic, you will meet members of the adult CF team, such as the consultant and CF nurse. The physiotherapist, dietician and psychologist will cover paediatrics and adults. They will discuss your transfer with you and you will have plenty of time to ask questions.

You will have the opportunity to visit the adult ward and the adult clinic before your transfer. You may choose to be admitted to Fistril (adolescent ward) up to the age of 17.

It is often helpful to receive a joint home visit from the paediatric and adult CF nurses, so that your transfer can be co-ordinated smoothly.

When will I transfer?

When you are 16 years old.

When are adult CF clinics held?

These are held on the first, second and fourth Wednesday of each month, in the afternoon. However, if these are fully booked, or you need to be seen sooner, we can arrange for you to be seen by the consultant at an alternative time (often a Tuesday or Thursday afternoon in a general respiratory clinic). During CF clinics, patients are segregated in the same way as in the adolescent clinic.

What happens if I need admitting to hospital?

If you feel you may need to be admitted to hospital, first contact your CF nurse, Monday to Friday 8am-4pm. Outside these hours, contact Fistrall ward, Wellington ward or Roskear ward directly, requesting admission. Phone numbers are given at the end of this leaflet.

You will be admitted into a side-room on the adult ward, possibly with en-suite bathroom. We will encourage you to self medicate, but if you feel unwell, you may wish the nursing staff to do this for you.

Can I administer intravenous antibiotics at home?

This will be at the discretion of your CF nurse and consultant. Your safety is paramount. If you need intravenous antibiotics and are not too unwell, you may wish to administer these at home. However, you will need to have your first dose (or first and second doses if you haven't had the antibiotic before) supervised in hospital. This will involve a morning or afternoon at the Respiratory department, where either the CF nurse will access your portacath or the Vascular Access team will insert a mid-line. Pre-mixed intravenous antibiotics will have been delivered to your home. The CF nurse will supervise you administering these, to check you can give them safely.

You will then need to remain in the department for a short time afterwards in case of any side-effects. You will also be given verbal and written instructions on your intravenous antibiotic therapy.

If you have never administered intravenous antibiotics at home, but now would like to, a short in-patient stay of 2-3 days is recommended. You will be taught how to self-administer safely.

You may need to have antibiotic blood levels taken during the course, so you will need to make sure you are available for this.

Will I have regular reviews?

Once a year, your CF nurse will co-ordinate a full annual review.

Your annual review will include:

- a glucose test (to prepare for this, you will need to fast the night before).
If you are diabetic, you will not need this test
- blood tests
- an exercise test
- a lung function test
- a chest X-ray
- an ECG (a tracing of your heart)
- other routine tests.

Your review also gives you the chance to discuss your CF, including any problems you may be experiencing. You will also be seen by the dietitian and physiotherapist separately for their part of the annual review, which may be on a different day.

Adult CF team contact details

CF nurse – Ruth Holding

Tel: 01872 252640 8am-4pm Monday - Thursday, 8am-12.30pm Fridays
(answerphone out of hours)

Mobile: 07775 035362

email: ruthholding@nhs.net

Consultant – Jonathan Myers

Tel: Secretary Melanie James and Catrina Rowe 01872 252732 9am-4pm
(answerphone out of hours)

Dietitian – Katrina Walker

Tel: 01872 252409

Physiotherapists

Claire Eddy Tel: 07917 594764

2nd physio Tel: 07917 594747

Clinical Psychologist

Tel: 01872 354353

Ward telephone numbers

Fistral (adolescent ward): 01872 253186

Wellington (adult ward): 01872 252100

Roskear (adult ward): 01872 252040

Feel free to contact the wards for telephone advice or to arrange admission out of hours.

Your transfer date is:

If you would like this leaflet in large print, braille, audio version or in another language, please contact the Patient Advice and Liaison Service (PALS) on 01872 252793

