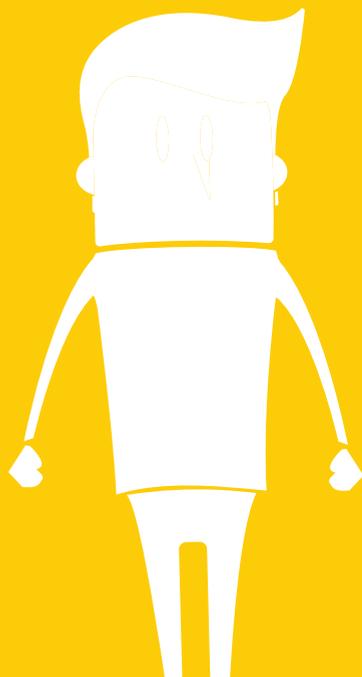


# **Cystic** **Fibrosis** *our focus*

**All about the adult  
cystic fibrosis service**



# All about the adult cystic fibrosis service

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## Lay Introduction to Cystic Fibrosis Service Specification

Since April 2013, NHS England has taken on direct responsibility for many of the services delivered by the former Primary Care Trusts (PCTs). Among these are the ‘**commissioning**’ (planning and purchasing) of services for people with cystic fibrosis (CF). There is a ‘Service Specification’ for CF services, which is part of a legal contract between NHS England and the organisations (hospitals) that provide these services. This document summarises what adults with cystic fibrosis can expect as a result of the new Service Specification.

## What is a Cystic Fibrosis (Adult) Service Specification?

The Specification clearly describes the services, care and outcomes that people with cystic fibrosis can expect from these centres. The Specification also outlines the way in which Adult CF centres should deliver care to adults with cystic fibrosis. It was developed in consultation with experts in CF, in conjunction with lay representatives of people with CF and their carers.



## What is an Adult Cystic Fibrosis Service?

An Adult CF Service is a comprehensive package of specialist care for adults who have cystic fibrosis. The Service has to be 'high quality'; ie it must be effective, deliver a positive patient experience and be safe<sup>1</sup>.

Service providers are hospitals and the NHS Trusts that run the hospitals. A CF service must continue to provide support for adults with CF throughout their lives from the time of transition from a paediatric (children's) service. The Transplantation Centre takes over responsibility for providing care to people with CF who have undergone a lung transplant.



<sup>1</sup>This definition of quality is written down in the Health and Social Care Act 2012, and is expected of all NHS providers of healthcare.

## **What is in the Adult Cystic Fibrosis Service Specification?**

The Specification describes in detail what each specialist Adult CF centre must make available to every adult with cystic fibrosis.

### **Here are some of the key points from the details of the Specification that adults with CF can expect from their CF service:**

- for all members of the CF Team to be specialists in, and up to date with, CF;
- to be reviewed regularly in clinic two to three monthly and to be seen by a doctor, nurse, physiotherapist and dietitian at each routine appointment;
- to have access to psychologist and social worker;
- to be admitted to a ward specialising in CF care;
- to be admitted to an individual room with en suite bathroom facilities;
- to be admitted within 24 hours for urgent cases;
- to be admitted within seven days for planned admissions;
- to be seen by a CF consultant twice a week when in hospital;
- to be offered a physiotherapy session twice each day, including weekends, when in hospital;
- to have access to a CF nurse and dietetic input when in hospital;
- to be able to start intravenous antibiotics on any day of the week;

- to have access to appropriate recreational facilities;
- clinic visits and tests to be co-ordinated to minimise visits when possible;
- to have CF support in the community arranged as necessary;
- to have access to advice from a CF specialist 24 hours a day, seven days a week;
- the CF service to meet their urgent CF care needs 24 hours a day, seven days a week;
- to be offered an Annual Review once a year;
- to practise the highest quality hygiene and isolation to reduce the risk of picking up infections whilst in or at hospital; and
- the CF service to have access to appropriate specialists: for example diabetic, liver and X-ray specialists, and fertility services.

**There is much more detail in the full Service Specification which is available online at [www.england.nhs.uk](http://www.england.nhs.uk).**

## What to do if you are not satisfied with your service

If you feel that your CF service is not meeting these standards you should discuss this with your team in the first instance. If you are still not satisfied then should use your hospitals complaints procedure.

## Who evaluates the Service Specification?

A number of measures are included in the Specification to help the NHS decide how well or poorly the Service is being delivered by Adult CF centres.

These measures include specific numbers, such as average lung function and weight, and how many people have certain chronic infections. The experiences of people with CF are also included, such as feedback on communications and individual quality of care.

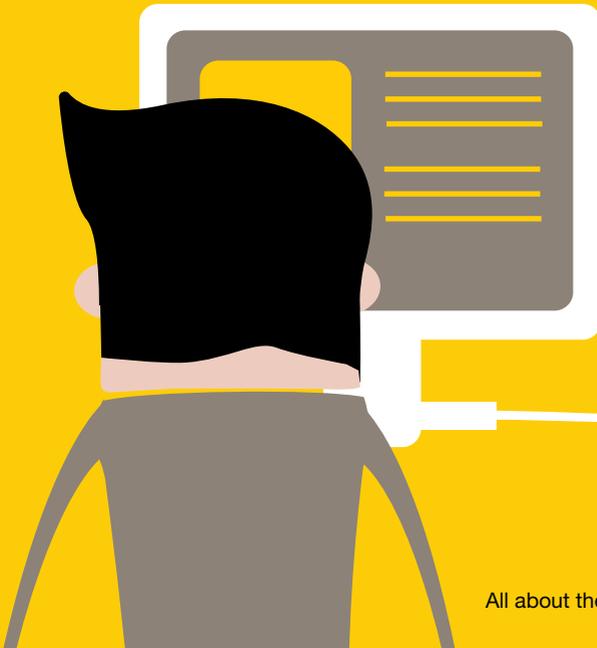
NHS England has a duty under the NHS Constitution and the Health & Social Care Act 2012 to review the quality of the services it delivers, aspire to excellence and ensure transparency and accountability to the people it serves. In cystic fibrosis, we use the UK CF Registry to provide high quality information about the performance of CF centres. The Cystic Fibrosis Trust works with NHS England, the British Thoracic Society, the British Paediatric Respiratory Society and engages with the CF community to investigate other ways we can produce useful information about the care people with cystic fibrosis receive.



## Find out more

**Links:** Use the links below to find out more about what should be available to you, or about research into cystic fibrosis.

- **Cystic Fibrosis Trust:** [www.cysticfibrosis.org.uk](http://www.cysticfibrosis.org.uk)  
for Peer Review reports and national registry reports, and much more.
- **NHS England:** [www.england.nhs.uk](http://www.england.nhs.uk)  
For the full service specification, for other documents and further information, search 'cystic fibrosis'
- **The British Thoracic Society:**  
[www.brit-thoracic.org.uk](http://www.brit-thoracic.org.uk)
- **The British Paediatric Respiratory Society:**  
[www.bprs.co.uk](http://www.bprs.co.uk)



# Cystic Fibrosis Trust

**Produced in conjunction  
with the NHS England  
Clinical Reference Group  
for Cystic Fibrosis.**

**[cysticfibrosis.org.uk](http://cysticfibrosis.org.uk)**

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