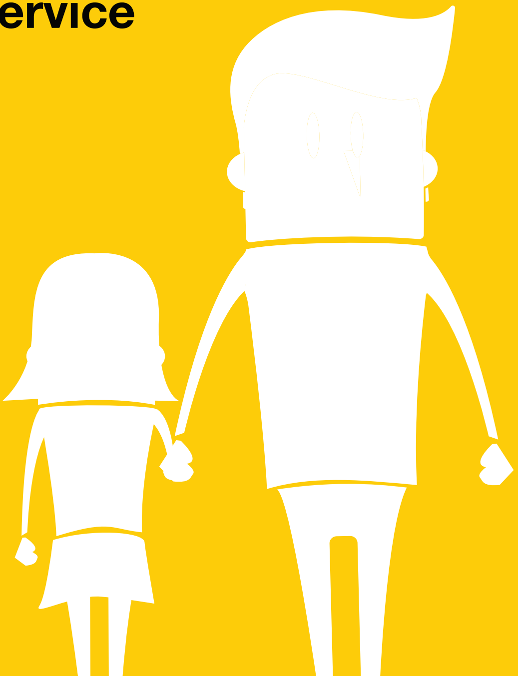
Cystic Fibrosis our focus

All about the children's cystic fibrosis service



All about the children's cystic fibrosis service

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). Amongst 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 children with CF, and their carers, can expect as a result of the new Service Specification.

What is a Cystic Fibrosis (Children) Service Specification?

The Cystic Fibrosis (Children's) Service Specification is a legal document between NHS England and children's CF centres in England.

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

What is a Children's Cystic Fibrosis Service?

A Children's CF Service is a comprehensive package of specialist care for children who have cystic fibrosis. The Service has to be 'high quality', ie it must be effective, deliver a positive patient experience and be safe[1].

Service providers are hospitals and the NHS Trusts that run the hospitals. A CF service must continue to provide support for children with CF throughout their lives from the time of diagnosis to the time of transition to an adult service.

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[1] 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 Children’s Cystic Fibrosis Service Specification?

The Specification describes in detail what each specialist Children’s CF centre must make available to every child with CF.

Here are some of the key points from the details of the Specification that children with CF and their carers can expect from their CF service:

- for standards of care to be the same whether seen at the ‘network’ or ‘specialist centre’;
- if some care is delivered through a network, care for all patients should be directed by a specialist centre;
- for all members of the CF Team to be specialists in, and up to date with, CF;
- to be reviewed regularly at clinic at least every two to three months, or more often if needed;
- to be seen by a doctor, nurse, physiotherapist and dietitian at each routine appointment;
- to have access to a CF psychologist and CF 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 have appropriate access to blood tests, venous lines and other vascular access at all times;
- to have access to sedation for procedures when needed;
- 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 physiotherapy sessions 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 IV antibiotics on any day of the week;
- to have access to appropriate play and learning facilities when in hospital;
- Clinic visits and tests to be co-ordinated to minimise visits when possible;
- to receive support in the community from the CF team, including open access to children's nurses with specific experience in CF;
- 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 24/7;
- to be offered an Annual Review once a year, usually at and always involving review by the specialist centre;
- 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 such as diabetic, liver and X-ray specialists.

There is much more detail in the full Service Specification which is available online at 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 then you should discuss this with your team in the first instance. If you are still not satisfied then you should follow 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 children's CF centres.

These measures include specific numbers, such as how long people with CF live, 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 for Peer Review reports and national registry reports, and much more.
- **NHS England:** 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
- **The British Paediatric Respiratory Society:** www.bprs.co.uk

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

cysticfibrosis.org.uk

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