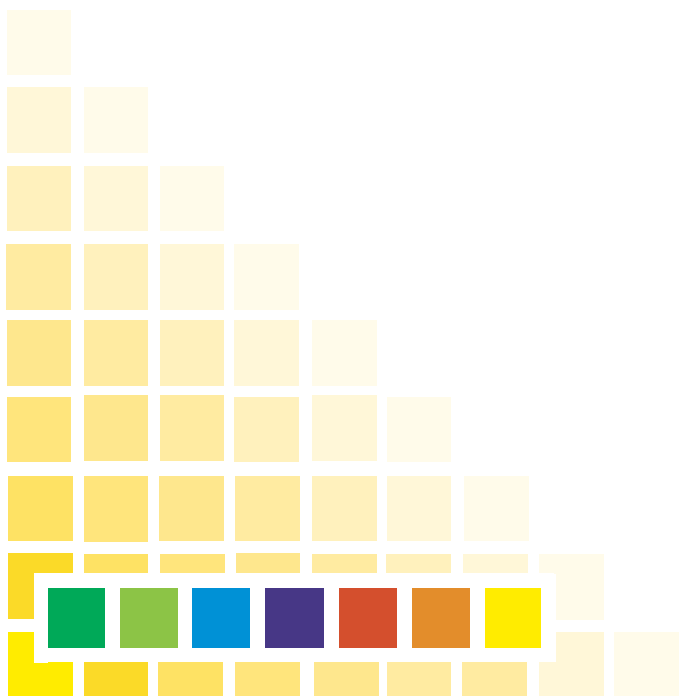


Royal Brompton Hospital

Your Child's Cystic Fibrosis Clinic



Royal Brompton and Harefield NHS Trust is a leading centre in the care of children and adults with cystic fibrosis (CF). Our paediatric CF clinic offers a team approach to all children and their families. We aim to provide a comprehensive (holistic) approach to CF care. Our children's outpatient department at Royal Brompton Hospital is situated in Fulham Wing on the Fulham Road.

Our paediatric team includes:

- consultants
- CF research registrars and clinical registrars
- CF nurses including our homecare nurses
- clinical psychologists
- social workers
- ward teachers
- physiotherapists
- dietitians
- play specialist

Regular clinics

Clinics are held in the children's paediatric clinic on:

- Monday - 9:00a.m. to 1:00p.m.
- Friday - 1:45p.m. to 4:30p.m.
(but not on the first Friday of every month)

The majority of patients are seen in our outpatient department regularly, usually every two months, as recommended in the clinical guidelines from the Cystic Fibrosis Trust, the British Paediatric Association and the British Thoracic Society. If your child's care is shared with your local hospital your child will be seen here at least once a year. This is called the 'annual assessment'. Visits to Royal Brompton Hospital may be more frequent according to the specific needs of the individual.

Our medical team are all experienced in CF care. Although you may not be seen by your consultant at every visit, your child's care will be discussed with him / her.

Clinics

You may notice that our clinics are busier at some times than others. To avoid a long wait in clinic it is important that you keep to your appointment time. This will help prevent long waiting times and congestion. Please tell us in advance if you are unable to keep your appointment.

- **extra clinic appointments:**

If your child is unwell and needs to be seen before their next clinic appointment they can be booked into the next CF clinic or be seen on the ward. If at any time you are concerned about the health of your child please contact a member of the CF team so they can arrange where you will be seen.

- **visiting health professionals:**

Visiting doctors or nurses sometimes come to the clinic to learn more about CF care. We will check with you that you are happy to have them at your child's consultation. If you don't want anybody else there, please tell a member of the CF team in the clinic. You do not have to give a reason and your decision will not affect your child's treatment in any way.

Research projects

We are involved in new projects to increase our understanding of CF and help us offer better treatment. We may ask if you or your child would like to take part. If so, we will give you a full explanation of the project and ask you to sign a consent form. Participation is voluntary and you or your child may refuse or withdraw consent at any time without giving a reason. As before, your decision will not affect you child's treatment or care.

Annual assessment

This is carried out once a year, usually around the time of your child's birthday. It involves:

- **ventilation scans**

We do these on Mondays for children under six years old. You don't need to make any special preparations for this scan which assesses the air supply to the lungs. Your child will breathe in a special gas through a mask which will need to stay on his / her face whilst pictures are taken. The pictures detect the radioactive particles coming from the gases using a special camera.

Radiation is used as sparingly as possible and the benefits of the investigation far outweigh any risks to your child's health. If you have any concerns, please contact us.

- **lung function for children aged 6 years and above**

A special blowing test that measures the capacity of the lungs and airways (how big the lungs are) and the flow of air through the lungs (how well they work).

- **chest xray**

To check the appearance of the lungs.

- **blood test**

A local anaesthetic cream is used to numb the area before the blood test is done. The blood test helps us monitor your child's health and look at things that might cause us to change your child's treatment for example liver function, glucose and vitamin levels and any bacterial or fungal infection.

- **other tests**

We may also need to perform other tests such as bone density, liver ultrasound, faecal fat collection, or glucose tolerance tests. Each test will be explained to you if your child needs it.

We collect the results and enter them onto our computer database. We then send a report including blood results, ventilation or lung function, height and weight charts to your GP and your shared-care consultant. If you would like a copy please ask the doctor at the time of the assessment. The results take at least two weeks and will be discussed at your next clinic visit.

Paediatric cystic fibrosis nurse

You will see our nurse every time you come to clinic. He / she is there to measure height, weight and lung function and to monitor oxygen. These are important measurements to see how your child is doing. Our nurse is also there to help with any problems you may have with treatment, either physically, emotionally, psychologically or socially.

Out of clinic the CF nurse carries a bleep and also has an answerphone so that you can contact him / her with any difficulties or queries you may have.

tel: 020 7352 8121 bleep 1213
answerphone: 020 7351 8755

The doctors

The doctor you see from the medical team will:

- discuss how your child has been since the last visit and check current medication
- encourage questions and listen to concerns you may have about your child's progress
- perform a physical examination
- encourage adolescents to be seen on their own as well as with their parents.

Children's cystic fibrosis home care nurses

The CF team includes two home care nurses who can visit children and their families within the M25. They are a unit between hospital and home and can discuss the service with you if you feel you would benefit from it.

Physiotherapists

There is a clinic-based physiotherapist who is available to check chest clearance techniques, obtain samples of your child's sputum and take cough swabs. The physiotherapist will also give advice on any physiotherapy issues and provide any necessary equipment. It is important that your child is seen by the physiotherapist at each visit, particularly at the annual review, and that your child's nebuliser / compressor is serviced once a year. Remember that techniques will change as your child grows. Regular review is important. If there are any physiotherapy queries outside clinic times please contact the physiotherapy department on tel: 020 7351 8088.

Dietitian

Our dietitian is available in all clinics. He / she will review your child's appetite, growth and pancreatic enzyme replacement therapy. We will carry out a more detailed nutritional assessment as part of your child's annual assessment.

Paediatric medical social worker

We may refer you to the paediatric social worker, or you may refer yourself. He / she will work with you in:

- assessing what practical, social, emotional and psychological support your child needs
- providing counselling at the time of diagnosis and at other times when there are extra stresses within the family
- advising you on financial help available from the Benefits Agency and other specialised charities
- with your agreement, the paediatric social worker will liaise with your local authority and also other local agencies to make sure you get the services and support you need.

Paediatric clinical psychologists

Our clinical psychologists provide support and advice to children and young people with CF, their families and / or carers. You can speak to them directly in our outpatient clinic or ask to be referred to them by one of the other team members.

There are many things that the clinical psychologists may be able to help with. These include:

- eating
- sleeping
- general behaviour
- coping with treatments
- fears and worries about the illness
- other areas of your child's life.

Each clinical psychologist carries a bleep and also has an answerphone. Please call them if you would like to know more about the services they provide.

tel: 020 7352 8121 ext: 2015 / 8239 or bleep: 6053 / 1228

Chelsea Children's Hospital School

Situated on level four of Sydney Wing, just outside Rose Ward, the school ensures that your child can continue their education while in hospital. We provide a broad and balanced curriculum in line with the national curriculum, making sure we consider each child's individual needs. In order to do this, staff at the school liaise closely with your child's normal school.

We can also help with educational issues which might arise when your child is not in hospital. If you would like any help or information please contact us.

Parents' evenings are held once every three months. These are social as well as informative occasions for both parents and staff. They give you the chance to meet and chat with staff without your children. A guest speaker talks on a particular subject for about 30 minutes. The evenings are held in the seminar room, Sydney Wing on Wednesday evenings, 7:00p.m. to 9:00p.m. For further details and to offer suggestions for a talk, please contact our CF nurse on tel: 020 7351 8755

Useful contact numbers at Royal Brompton Hospital:

- Royal Brompton Hospital (main switchboard)
tel: 020 7352 8121
- Cystic fibrosis secretary
tel: 020 7351 8764
- Paediatric cystic fibrosis nurse
tel: 020 7351 8755 (answerphone)
tel: 020 7352 8121 bleep: 1213
- Paediatric cystic fibrosis research registrar
tel: 020 7352 8121 bleep: 0036
- Children's cystic fibrosis homecare nurses
tel: 0973 173969
- Dietitian
tel: 020 7351 8465
tel: 020 7352 8121 bleep: 7101
- Physiotherapy department
tel: 020 7351 8088
- Medical social worker
tel: 020 7351 8463
- Out of hours - after 5.30pm or weekends
please contact the on-call registrar
tel: 020 7352 8121 bleep 1237

Notes

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