

The Cystic Fibrosis Service at GOSH

A close-up photograph of a baby lying on a colorful, patterned blanket. The baby is wearing a black and white striped sweater. The background is a vibrant green blanket with various colorful patterns, including a red fox-like animal and blue and orange shapes.

Information for families
of newly diagnosed children
– what to expect in the first year

Great Ormond Street Hospital
for Children NHS Foundation Trust

Since 2007 almost all children with cystic fibrosis (CF) are diagnosed in the first few weeks after birth by newborn screening (heel prick test). These babies are usually very well and show no signs of any problems. Our aim is to keep these babies as healthy as possible and begin treatment at the first sign of any problems to avoid damage to the lungs and maintain a healthy nutritional state. More rarely these days the diagnosis of CF is made later in childhood often due to on-going chest or tummy problems.

We hope that the following information will give you some idea of what to expect, in terms of hospital visits and treatment during the first year. Please, remember this does not replace contact with the CF team. We are here to help and you can contact us if you have any queries or concerns regarding CF or your child's health. Further information is also available on the GOSH website at www.gosh.nhs.uk/medical-conditions/clinical-specialties/cystic-fibrosis-information-for-parents-and-visitors.

What happens immediately after we have been told the diagnosis?

Within a few days of the diagnosis of CF being made, you will begin to learn about the various aspects of CF and start some of the regular treatment required. The first step is an appointment at GOSH when you will meet each member of the CF team, who will begin to explain their roles and treatments which may be necessary. Our psychosocial team (psychologist and social worker) will also meet you and are here to offer you as much support and advice as you need.

Various treatment may be initiated over the next few weeks, depending on each baby's needs. These often include starting regular preventative antibiotics, enzymes to help digestion and supplementary vitamins as well as a programme of physiotherapy (which consists of regular physical activity and where necessary specific airway clearance techniques).

Our clinical nurse specialist and physiotherapist will usually visit you at home within the first month to offer further advice and support. The rest of the team are always available to you via telephone or e-mail and if necessary can arrange to see you at the hospital.

The first outpatient clinic at GOSH will be approximately one month following the diagnosis. One of our CF consultants will always see you at this first appointment as will the rest of the CF team. More detailed information about our clinics is available on the GOSH website and in the leaflet *The cystic fibrosis service at GOSH*.

Then what?

Between one and three months after diagnosis

Over this time it is likely that you will become more and more confident about CF and what it means. At some point within the first three months, we will undertake some breathing tests (infant lung function), which help us to see how your babies lungs are working from a very early stage. These tests will of course be discussed and explained fully so that you understand why we feel they are helpful.

Your baby will be reviewed again in CF clinic, where you will have the opportunity to ask further questions or seek advice from any members of the team. The Clinical Nurse Specialist and/or Physiotherapist may visit you again at home depending on individual needs and you can of course always contact the CF team should you have any concerns at all.

After the first three to four months

We hope that over this time, we will be able to establish a routine of regular review and monitoring on an outpatient basis. Clinic appointments are usually every two months over the first few months (occasionally more frequently if necessary). After this time if your baby is very well and stable we may be able to spread the visits out a little but the vast majority of children with CF need to be seen on a two to three monthly basis to monitor progress, pick up any potential problems early and ensure that things are going well.

There will be various stages where you will need the different members of the team such as dietetic advice when it comes to weaning. The Clinical Nurse Specialist and/or Physiotherapist will visit you at home only if there are specific issues.

It is perfectly normal for small children to get coughs and colds, but it is very important that in CF coughs and chest infections are treated promptly with antibiotics. We will also take cough swabs at every clinic to monitor for signs of infection and will treat any relevant infection if one is found.

One year of age

At about one year of age we will undertake a thorough review – which we call an annual review and takes place once every year for all children with CF. There are some additional tests which we undertake at approximately one year of age, which allow us to get a good idea of the health of your baby's lungs.

The additional tests include a chest x-ray, to look at the lungs in more detail; blood tests; lung function test and a bronchoscopy. The lung function test is a breathing test and will be very similar to the test at three months. It will give us more information on how well your child is breathing. The bronchoscopy is a test which is performed under a short general anaesthetic, in which a flexible telescope is passed down the breathing tube and in to the lungs to allow us to check if there are any signs of infection. All these tests will be discussed at length and in detail with you at the appropriate time.



Important Information:

How to contact the CF Team at GOSH

We are very happy for you to contact us with any queries. In order that we can deal with them appropriately please use the following options:

TELEPHONE CONTACT

1. Normal working hours:

Cystic Fibrosis Office Direct

Line: 020 7762 6714

All telephone queries during normal working hours should be made via the CF secretary, Carol, who will direct your call to the appropriate member of the CF team. These calls are logged and will be answered at regular intervals throughout the day. Calls which are of a more urgent medical nature will of course be answered as a matter of priority and if necessary one of the nurses or our CF Fellow will be bleeped immediately.

The mobile phones carried by our outreach staff are not for general medical enquiries and you will be requested to call back to the above number (unless it is regarding a specific outreach visit).

2. Out of hours (for urgent medical issues):

Badger Ward:

020 74059200 Ext 8813

As a specialist centre GOSH CF unit provides out of hours advice for urgent patient

needs. The nature of the query will be assessed and wherever necessary the on-call respiratory doctor will be contacted and will return your call to discuss the problem.

E-MAIL CONTACT

CysticFibrosisUnit.Query

@gosh.nhs.uk

If you have a query that is not of an urgent nature you may wish to e-mail us – we now have a generic e-mail address for the CF team (personal e-mail mailboxes will no longer receive queries). Messages sent to the above address can be accessed by all of the team and we will ensure that the appropriate member of the team gets your message. Receipt of your e-mail will be acknowledged and you should expect to receive a response to your query within 2 working days. Please note that we have to be careful about the nature of information sent via e-mail due to the dangers associated with using public networks of any kind. If however, you would prefer us to use e-mail, we can do so providing a consent form is signed. You can request one of our e-mail information sheets and consent form next time you are in clinic or by telephone.

If you ever have any concerns regarding these arrangements or any other part of the CF service please contact Ammani Prasad, CF Unit Manager on the CF Office Direct Line.

Cystic Fibrosis Unit Contact Details

GOSH switchboard	020 7405 9200
CF Office	020 7762 6714
Badger Ward	020 7829 8813
E-Mail	cysticfibrosisunit.query@gosh.nhs.uk

© GOSH Foundation Trust June 2013

Ref: 2013F1484

Compiled by the CF Team

in collaboration with the Child and Family Information Group

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www.gosh.nhs.uk