

# Psychosocial support for parents of babies diagnosed with Cystic Fibrosis

Information for families

Great Ormond Street Hospital  
for Children NHS Foundation Trust

# **This information sheet explains the psychosocial support available at Great Ormond Street Hospital (GOSH) for parents of babies diagnosed with cystic fibrosis (CF).**

## **Clinical Psychology**

The Cystic Fibrosis (CF) Service at GOSH has included a psychologist as part of the team for over twenty years. It is accepted that all parents will naturally be feeling distressed after being given the diagnosis of CF in their baby. The Clinical Psychologist in the CF team will be available to meet with all parents (and other family members if required) very soon after diagnosis.

In the early stages, the psychologist's role is to offer support, to listen and advise on coping – in most cases to reassure parents that their reactions are completely normal. Often mothers and fathers react in different ways, show different emotions and focus on different aspects of CF. This is also normal and many parents find it helpful to hear that people cope in different ways, there is no correct response and people have their own pace of dealing with information.

Parents very often wonder who else to tell – family and friends. There is a frequent feeling of wanting to keep the diagnosis to just a small number of people initially. Other parents need to inform as many people as possible to gain their support. The psychologist can help parents think through the pros and cons of who to tell, for what reason and why, helping the parents go at their preferred pace.

The psychologist has knowledge of CF and how managing CF treatment can impact on daily life. One role of the psychologist is to help parents think through how they will be able to manage medicines and know when their child is ill. It is quite common that parents feel a sense of panic after diagnosis, that they will not have the skills to manage medicines. The psychologist helps with the emotional impact of managing treatment alongside the practical advice from other team members.

In the initial days and weeks following diagnosis, parents often feel that they have been given a lot of information and worry they won't remember it. It is common that when people experience strong emotions, they do not retain information in the usual way. The psychologist helps go over all new information and find ways to ensure better understanding and memory of all the new CF education. The psychologist can answer questions on what it is like for a child growing up with CF, what their understanding will be of CF, when they tend to ask questions and how to answer. For many parents, these questions come to mind even though the baby is a long way off those developmental stages.

Some parents find it reassuring to know we have answers to those questions, we learn from the experience of others and can pass on that knowledge and advice to support them in the future. The psychologist can also help parents consider other children in the family and their understanding of CF, what it is like to have a brother or sister with CF and any questions or concerns they might have.

The psychologist is available at all CF clinics and for contact in between appointments via the CF Office phone and email. For many families having a chat in clinic is enough to keep ticking along. There are occasions when there is not enough time in routine clinics to have a longer talk about thoughts, feelings and emotions. If required, the psychologist can give separate longer appointments for parents outside of the CF clinic.

## Social Work

Social work services are an integral part of the multidisciplinary CF team. The Social Worker strives to see all families with a newly diagnosed baby during their first outpatient appointment, and then at all visits to hospital as outpatients or inpatients. Coming to hospital can, for some families, be very expensive and time consuming and the social worker can help with incurred expenses.

During the first few appointments, the social worker provides assessment of the emotional, practical and financial impact of the new diagnosis on a family and can provide support in the following areas:

- Housing
- Appropriate benefits, entitlements and other resources
- Grants/Wishes/Other Financial support
- Care and disability support services
- Family, relationship and carer issues (including support for siblings and parenting skills)
- Advocacy and emotional support around new diagnosis
- Education
- Child Safeguarding (and protection, on the rare occasions it is needed, effective information sharing and referral and liaison with other safeguarding agencies)

The social worker can negotiate and liaise with other agencies (such as social care, education, local services) to help families that are coming to GOSH.

## Family Support Workers

All families can also use the services of our family support workers. The family support worker works together with other services to enable children and families to cope with the stress of diagnosis and the experience of coming and staying in hospital. They can provide practical advice and assistance to children and families on welfare, benefits and financial support and many other subjects.

## Citizens Advice Bureau

There is also Citizens Advice Bureau located at GOSH on Level 2. The Citizens Advice service provides free, independent, confidential and impartial advice to everyone (inpatients or outpatients) on their rights and responsibilities and can help resolve legal, financial and other problems.

### Notes





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Great Ormond Street Hospital for Children NHS Foundation Trust  
Great Ormond Street  
London WC1N 3JH

[www.gosh.nhs.uk](http://www.gosh.nhs.uk)