

# The Cystic Fibrosis (CF) Home Care Service at GOSH: information for families

The Cystic Fibrosis (CF) team at Great Ormond Street Hospital (GOSH) offers a home care service, with visits carried out by a member of the CF team or by a colleague in a shared care centre – depending on where you live and if appropriate. We work closely with shared care centres and community nursing teams to make sure assessment, care and support needed for your child and family are met in a timely manner. This information sheet from GOSH explains how to access the CF Home Care Service and what to expect.

Please note: During the coronavirus (COVID-19) pandemic, the Home Care Service is carrying out visits remotely using telephone or video conferencing. Please contact us in the usual way to discuss how to arrange a virtual visit.

Any member of the CF multidisciplinary team can request home care visit. You, as parents, and your child can also ask for one.

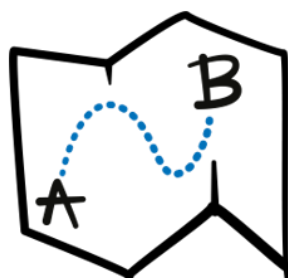
- The CF Nurses can visit on Mondays, Wednesdays, Thursdays and Fridays between 9am and 5pm.
- The CF Physio can visit Monday to Friday from 9am to 5pm.

## How the CF Nurses can help

From initial diagnosis through to when your child transfers to adult CF services, the CF Nurses offer guidance, advice and teaching so you feel fully supported. We offer specialised care so that children have the best health possible, carrying out daily activities and attending school.

Some of the support we can offer includes:

- **Clinical respiratory assessment** – this includes listening to your child's chest, monitoring the amount of oxygen in their blood (saturations), collecting cough swab or sputum samples as well as giving advice or starting a treatment plan if required.
- **Mid IV and end of IV review** – If your child requires routine intravenous (IV) antibiotics to maintain their health, we complete an assessment of progress half way through their course of treatment and again at the end. Where possible we complete this at your home.
- **Taking blood samples for monitoring** –if your child is on a particular type of treatment which requires monitoring, for example, checking drug levels in the blood, we can arrange to take the blood samples at home.
- **Lung function at home** – this is completed as part of a general assessment or as an additional appointment. For example, if your child had decreased lung function in clinic, the



consultant may ask for a repeat lung function in two weeks' time to assess progress.

- **Specialist support** – Having Cystic Fibrosis can be challenging at times – we often describe it as a rollercoaster journey. Our specialist CF Nurses will always discuss anxieties or concerns on the phone first and then offer a support visit if needed.

The first year of diagnosis can be especially unsettling. We offer increased home visits for support during this time. Remember, there does not necessarily have to be a clinical need for a visit – your mental health and wellbeing is just as important.

- **Weight and diet monitoring and advice** – this is usually after your child has seen the CF Dietitian in clinic.
- **Psychosocial support** – this is sometimes carried out jointly with the CF Social Worker
- **Teaching to school and nursery staff** – Once your child has a place at nursery or school, a CF Nurse will talk to staff there to develop a care plan for your child.

We can also advise on Risk Assessment if needed, both for day to day activities as well as special occasions such as school trips. This may involve developing a treatment timetable for residential trips and holidays, as well as training school staff to use medications and equipment to complete treatments.

- **Helping your child and family understand CF treatments** – If your child starts a new treatment or their current treatment needs monitoring, we can talk to you and show you what to do. If you or your child are struggling with a treatment, or having some issues of compliance we can complete a 'refresher' teaching session. Treatment sessions are available for the extended family if required.

- **Joint visits with shared care centre or community nursing colleagues** – We may carry out joint visits with your local team(s) if we think this will help your child and ensure everyone is up to date. If your child is under five, we can also visit with your local Health Visitor.

As well as carrying out home visits, the team can also carry out video conference calls with you at home. We assess if this is possible and appropriate for your particular concerns and/or needs.

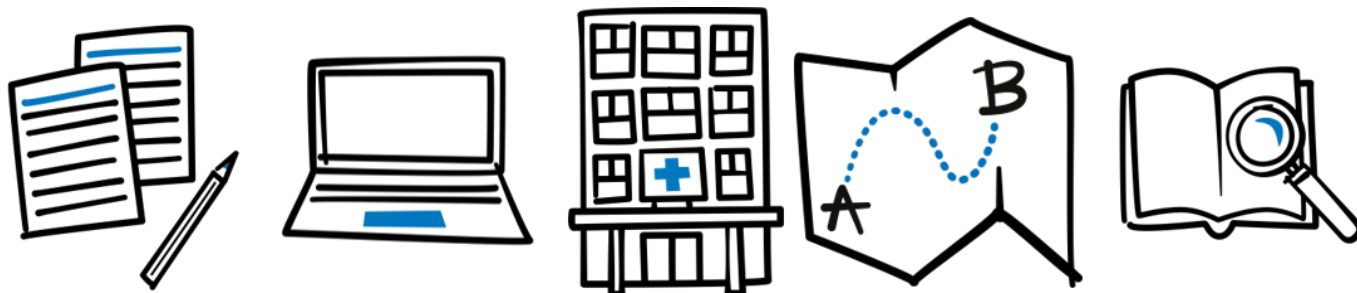
The Home Care Service can also arrange to see your child at school or nursery if needed.

## How the CF Physio can help

The CF Physio can advise you on airway clearance techniques, inhaled therapies and physical activity, sport and exercise.

Some of the support we can offer include:

- **Education and support** – we can provide physiotherapy-specific education and support to you and your family at home at any time. The first year of diagnosis often presents a lot of questions so we offer increased home visits to help answers these at this time. We can also provide education and support to nursery and school staff alongside the specialist nurses.
- **Monitoring of airway clearance techniques** – It is always helpful to have the occasional refresher to make sure you and your child are following the treatment programme as well as possible.
- **Teaching new techniques** – As your child grows older, different methods of airway clearance might be more suitable. We can teach you how to do these or offer a reminder following clinic visits or annual review.



- **Advising about physical activity, sport and exercise** – We encourage your child to take part in as much physical activity and exercise as possible. We can help support you and your child with activity ideas at home, school and out in community facilities, for example at a local gym. If your child wants to try a particular sport, activity or club, we can also give you and the providers advice and suggestions.

## Booking an appointment or visit

Please call the CF office on 020 7762 6714 – we will note your request and call you back to discuss. You can also email the CF team at [cysticfibrosisunit.query@gosh.nhs.uk](mailto:cysticfibrosisunit.query@gosh.nhs.uk) or contact the team via MyGOSH once you have registered. Details about MyGOSH are at [www.gosh.nhs.uk/your-hospital-visit/mygosh](http://www.gosh.nhs.uk/your-hospital-visit/mygosh)

**Even if you have a shared care centre or community team, please contact the GOSH CF team to book an appointment or visit.**

## Your child's Shared Care Centre

You live in an area applicable for shared care (details below)

Not applicable ☐

**Hospital**

**Consultant**

**Community Children's Nurse (CCN) team**

**Contact details**

