

Information for families

Great Ormond Street Hospital for Children NHS Trust

Cystic fibrosis (CF) requires time consuming and often complicated treatment regimens that have to be carried out on a daily basis. The CF team at Great Ormond Street Hospital acknowledge the demands this makes on children with CF, their parents and family life in general.

For those who require additional support, we also provide a home visiting service giving individualised care by a CF specialist nurse and CF specialist physiotherapist.

What we hope to achieve:

- provide support, guidance and education for patients and families regarding diagnosis, physiotherapy treatments, nutrition (diet and enzymes), medications, new treatments, home IV antibiotic therapy
- support transition to adult services
- decrease the length of hospital stays allowing the patient and family to return to a normal routine and lifestyle
- decrease the need for subsequent admissions or clinic visits
- provide education for local health care professionals and schools
- support during palliative care

What we can do at home:

- assess techniques and effectiveness of treatments being carried out
- assess clinical progress during a home IV antibiotic course
- perform lung function tests, drug level monitoring, blood sampling, implantable port flushes, weight and dietary monitoring and gastrostomy advice
- assess airway clearance physiotherapy treatments, monitor exercise regimens and provide general musculoskeletal advice where required
- liaise with local hospitals, community children's nurses and schools

Where you will be seen:

- at home
- at school or nursery.

When will you be seen:

- Monday to Thursday from 8am to 6pm for nurse visits
- Monday to Friday from 9am to 5pm for physiotherapy visits

How long will we see you for?

- the length and number of visits required will depend on:
 - the individual and the clinical circumstances
 - the amount of support you already have available from other community agencies

How to contact the CF Homecare team:

- Contact the CF homecare nurse specialists on 07979 770 292
- Contact the CF homecare physiotherapist on 07824 821 412

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