

Cystic Fibrosis *our focus*

Support for all

Introduction

The Cystic Fibrosis Trust provides a range of information and support services for people affected by cystic fibrosis.

Our helpline offers a listening ear and someone to talk to in confidence for anyone who is affected by the condition. People with CF, their parents, relatives and friends, health professionals and teachers can access the helpline for information, advice and support.

Our support team can help with a range of issues, such as receiving a CF diagnosis, starting school, leaving home, employment issues and support with welfare benefits claims.

We can also put families in touch with a trained parent volunteer who can share their experiences and offer a listening ear.

Written by the Cystic Fibrosis Trust.

Last reviewed July 2016.

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Benefits advice

If you require information and about benefits, you can contact our helpline on helpline@cysticfibrosis.org.uk or 0300 373 1000. Our Welfare and Rights Advisor can provide you with tailored, individual advice at any stage of the benefit claims process, from checking which benefits you could be entitled to, to supporting you through applications, appeals and tribunals.

Financial support

We recognise that cystic fibrosis can bring financial challenges. Our grants programme can provide help when it is needed most. We provide grants for:

- Goods and services to improve health and wellbeing (up to £350)
- Emergency situations (up to £150)
- Costs associated with transplants (up to £250)
- Funeral costs (up to £750)

Full details on our grants programme and other financial support available to people affected by cystic fibrosis can be found in our factsheet on Financial Help and on our [website](#).

CF Connect

We understand that cystic fibrosis can be an isolating condition for families. The risk of cross-infection means parents of children with CF cannot meet up as easily as they might like, and often miss out on the chance to talk to someone who knows how they feel. That's why we've set up CF Connect – a service where you can speak to a trained volunteer who also has a child with cystic fibrosis. CF Connect volunteers can offer a listening ear and the chance to share experiences in an understanding and supportive way.

To get in touch with a CF Connect volunteer, contact the helpline on helpline@cysticfibrosis.org.uk or 0300 373 1000.

The Cystic Fibrosis Trust helpline

Our helpline is available from 9am – 5pm Monday to Friday. Our trained staff can provide information, advice and support about all aspects of cystic fibrosis, whether you are coming to terms with a diagnosis of cystic fibrosis, would like information about financial support available or just need a listening ear.

Contact our helpline on helpline@cysticfibrosis.org.uk or 0300 373 1000. We're here to help.

Information we provide

Online and printed information

The Cystic Fibrosis Trust provides an extensive range of up-to-date information about cystic fibrosis in the form of publications, films and information packs as well as information on our website.

We produce a range of detailed factsheets, aimed at adults with cystic fibrosis and parents / carers of babies and children with CF, which cover many aspects of the condition. These include:

- Physiotherapy treatment
- Nutrition
- Genetic screening
- Bone health
- CF-related diabetes

For parents, we have produced a 'New Parent Pack', full of information and stories from families with children who have cystic fibrosis. We also have a starting school pack that offers detailed information for parents and teachers on how cystic fibrosis can be managed in the pre-school or primary school environment.

When a family member is diagnosed with cystic fibrosis, relatives can feel a sense of shock and often want to find out as much as they can about the condition. Our family and friends leaflet provides straightforward information about cystic fibrosis and how to support parents whose child has been diagnosed, and our helpline, website and forums provide support and access to more detailed information.

Twice a year we publish our magazine 'CF Life', which contains news, views and inspiring stories from the world of cystic fibrosis. If you don't receive the magazine, email us on helpline@cysticfibrosis.org.uk and we'd be happy to add you to our mailing list.

We have also produced a variety of information films, including:

Getting noseey about CF with Oli and Nush, a film aimed at four to eight year olds with cystic fibrosis,

...the rest is up to me, aimed at teenagers, and a range of films for families with a new diagnosis of cystic fibrosis.

Our films can be viewed at youtube.com/cftrust.

A full list of factsheets and other publications is available on our [website](#).

Website

Our website cysticfibrosis.org.uk contains a wealth of information about cystic fibrosis and our work, and a link to our web forums, where you can chat online with others affected by cystic fibrosis. All of our publications are downloadable from our website, and there's lots of information about how you can support the Cystic Fibrosis Trust through fundraising and other activities.

Special information packs

New parent pack

Each week in the UK, five babies are born with cystic fibrosis. To help parents come to terms with a diagnosis of cystic fibrosis, we provide a new parent pack. Written with the help of many parents of children with cystic fibrosis, the pack contains stories and messages from families, as well as easily digestible information about cystic fibrosis and about the support that is available. It also contains a short film, and a leaflet to help explain cystic fibrosis to family and friends. On our website you can find further information, including short films in which parents share their experiences of cystic fibrosis and a mum's diary of the months following her son's diagnosis.

Our parent pack and related resources can be viewed on our website and ordered using the online order form cysticfibrosis.org.uk/newdiagnosis.

Starting pre-school or primary school

Starting pre-school or primary school can be an exciting and daunting time for parents, particularly if your child has cystic fibrosis. To support families and schools through this transition, the Cystic Fibrosis Trust has developed a school pack, which is full of useful information and real-life examples of how people have managed the transition, with top tips for making the journey as smooth as possible. The pack includes a guide for parents, factsheets for schools, a healthcare plan template and a video showing the experience of one family. These resources can be viewed at cysticfibrosis.org.uk/school.

Thinking of starting a family? A guide for adults with CF and their partners

This guide contains clinical and factual information about how cystic fibrosis can impact on family planning decisions for men and women affected by the condition. It covers a wide range of topics including fertility, carrier testing, pregnancy, childbirth, adoption, surrogacy and parenthood. There are powerful case studies included to illustrate what the real experience of different aspects of family planning can be for people affected by cystic fibrosis. The booklet is available to view and order at cysticfibrosis.org.uk/fertility.

For further information about cystic fibrosis and the support we provide, contact our helpline on 0300 373 1000.

Further information

The Cystic Fibrosis Trust provides information about cystic fibrosis through our factsheets, leaflets and other publications.

Most of our publications are available through our helpline and can be downloaded from our website or ordered using our online publications order form. Visit cysticfibrosis.org.uk/publications.

The Cystic Fibrosis Trust helpline can help you with a range of issues, no matter how big or small. Our trained staff can provide a listening ear, practical advice, welfare/benefits information or direct you to other sources of support. The helpline can be contacted on 0300 373 1000 or helpline@cysticfibrosis.org.uk and is open Monday to Friday, 9am – 5pm.

Calls to 0300 numbers cost no more than 5p per minute from a standard BT residential landline. Charges from other landlines and mobile networks may vary, but will be no more than a standard geographic call and are included in all inclusive minutes and discount schemes. If you are worried about the cost of the call please let us know and we'll call you back.

You can also find more information at our website cysticfibrosis.org.uk.

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cysticfibrosis.org.uk



More factsheets available at:
cysticfibrosis.org.uk/publications

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The information included in this publication is not intended to replace any advice you may receive from your doctor or CF multidisciplinary team and it is important that you seek medical advice whenever considering a change of treatment.

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