

Cystic Fibrosis our focus

Cystic Fibrosis Trust publications
Unless otherwise stated, our publications
are all available to download online.

Hard copies of most of our factsheets and
leaflets can be ordered by emailing
enquiries@cysticfibrosis.org.uk. There is
no charge for any of our publications.

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Factsheets and leaflets

Our factsheets and leaflets are aimed at people with cystic fibrosis and their carers, and those who wish to find out more about the condition. They provide information about all aspects of cystic fibrosis, from screening and diagnosis to nutrition and treatment.

Cascade screening

Cascade screening for the cystic fibrosis gene may be carried out on relatives of someone who has been diagnosed with cystic fibrosis. This factsheet explains how cascade screening works and what it means to be a carrier of the faulty CF gene.

Cystic fibrosis-related diabetes

Cystic fibrosis-related diabetes (CFRD) is common in adults and adolescents with cystic fibrosis. This factsheet explains what diabetes is and why it can be associated with CF, and the care and treatment someone with CFRD should expect.

Cystic fibrosis and bone health

In people with cystic fibrosis, thinning of the bones can occur at an earlier age than in the general population. This factsheet describes how bone health can be affected in CF and the implications of this, how bone strength is measured, and options for prevention and treatment of thinning bones.

Cystic fibrosis... what exactly?

This leaflet is aimed at people who may not be very familiar with cystic fibrosis, and provides answers to some common questions people have about the condition including how it is caused, who gets it, the symptoms and the treatments available.

The Cystic Fibrosis Trust Support Service

This factsheet provides information about the information and support available from the CF Trust Support Service, including our helpline, welfare grants and publications.

Employment

Series of six factsheets covering various aspects of employment, including finding the right job, legal issues, and a factsheet for employers.

Financial help

This factsheet provides information about the financial support that may be available for people with cystic fibrosis and their families from the Cystic Fibrosis Trust and other organisations.

Finding out about cystic fibrosis – a guide for parents

This factsheet provides information about cystic fibrosis

for parents coming to terms with a diagnosis of CF in their child.

Higher education

Series of three factsheets aimed at teenagers or young adults considering higher education, including information for tutors and accommodation officers

Home intravenous therapy

This factsheet addresses some questions you may have about home intravenous antibiotic treatment and compares the advantages and disadvantages of home IVs compared to those given in hospital.

Housing for people with cystic fibrosis

Series of four factsheets about housing, including finding a suitable home, renting, buying and what to do if you have lost or may lose your home.

Late diagnosis (contact CF Trust to order)

This factsheet contains information about cystic fibrosis aimed at people who have been diagnosed with the condition in adulthood.

Lung transplantation in cystic fibrosis

This factsheet has been written to help people with cystic fibrosis who are considering lung transplantation. It contains information about the assessment procedure, waiting time, the operation and follow-up, and answers some frequently-asked questions.

Melioidosis and tropical travel

Melioidosis is a rare but potentially life-threatening infection that can be contracted in some tropical countries. This factsheet contains advice on how to reduce your risk of contracting the infection if travelling to a country where melioidosis is present.

Nebuliser therapy

Nebulised antibiotics are a common part of the cystic fibrosis treatment regime. This factsheet provides information on the different types of nebulisers available, how to look after your nebuliser and the types of medications that can be nebulised.

Nutrition: a guide for adults

This factsheet provides information for adults with cystic fibrosis on how to maintain good nutritional health.

Nutrition: a guide for children and parents

This factsheet provides information for parents and carers on how to maintain good nutritional health in children with cystic fibrosis.

Nutrition: a guide for feeding infants

This factsheet provides information for parents and carers on how to ensure good nutritional health in infants with cystic fibrosis.

Physiotherapy: airway clearance

Looking after the chest and keeping the lungs clear is extremely important in cystic fibrosis. This factsheet explains why it is important to keep the lungs clear and the various airway clearance techniques available.

Physiotherapy: treatment for babies and toddlers

Looking after the chest and keeping the lungs clear is extremely important in cystic fibrosis. This factsheet is an introduction to chest physiotherapy and its use in babies and toddlers with cystic fibrosis.

Portacaths in cystic fibrosis

A portacath (port) is a totally implantable venous access device (sometimes called a TIVAD for short), which is placed under the skin and is a means of delivering medication to the body easily and effectively. This factsheet provides answers to some common questions people have about portacaths.

Prescription charges

In England many people with cystic fibrosis still have to pay for their medical prescriptions. This factsheet provides information about prescription charges in England, including the current costs, how charging works, who is exempt, and the CF Trust's stance.

School and cystic fibrosis

This factsheet provides information about all aspects of cystic fibrosis and school for both teachers who have a pupil with cystic fibrosis, and for parents whose children with CF are just starting school, changing schools or have a new teacher.

Steroid treatment in cystic fibrosis

This factsheet contains information on steroid treatment in cystic fibrosis, including the different types of steroids, what they are used for, how they are given and their possible side effects.

The sweat test in cystic fibrosis

Sweat tests can be used to diagnose cystic fibrosis. This factsheet provides information on the sweat test, how it works, and why it is used.

Transition from paediatric to adult care:

Guide for young people

This factsheet provides information for young people about what to expect when moving from paediatric to adult care, and explains the differences between the two.

Transition from paediatric to adult care:

Guide for parents

This factsheet provides information for parents of a child undergoing transition from paediatric to adult care, and explains the differences between paediatric and adult care and what to expect after transition.

Transition from paediatric to adult care:

Guide for commissioners and hospital / clinical teams

The transition from paediatric to adult care should be a planned, collaborative process involving professional caregivers, the young person and family. This factsheet outlines how to ensure the transition process runs smoothly for your patients.

Urinary incontinence

Urinary incontinence may be experienced by females, and, to a lesser degree, males with cystic fibrosis. This factsheet explains why urinary incontinence may occur, and what help is available.

Consensus documents

Our consensus documents are specialist guidelines written by and aimed at for clinicians, scientists and researchers involved in cystic fibrosis care and treatment.

Only available online.

Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK

Pharmacy Standards of Care

Standards of Care and Good Clinical Practice for the Physiotherapy Management of Cystic Fibrosis

Laboratory Standards for Processing Microbiological Samples from People with Cystic Fibrosis

Antibiotic Treatment for Cystic Fibrosis

Methicillin-resistant *Staphylococcus aureus* (MRSA)

Bone Mineralisation in Cystic Fibrosis

***Pseudomonas aeruginosa* infection in people with Cystic Fibrosis. Suggestions for Prevention and Infection Control**

The *Burkholderia cepacia* complex – Suggestions for

Consensus documents continued

Prevention and Infection Control

Management of Cystic Fibrosis-related Diabetes Mellitus

Nutritional Management of Cystic Fibrosis

National Consensus Standards for the Nursing Management of Cystic Fibrosis

Other publications

Annual review

Read about the Cystic Fibrosis Trust's activities over the past financial year, and how your funds are helping us make a real impact on the lives of people affected by cystic fibrosis.

IS magazine

Our brand new magazine for everyone affected by cystic fibrosis, featuring information, news and inspiring stories from the world of cystic fibrosis.

Getting Nosey about CF with Oli and Nush

Our animated film aimed at children with cystic fibrosis aged four to eight, which explains what cystic fibrosis is with the help of Oli and his friend Nush the nosey ant eater! Can also be used in schools and hospitals as an educational tool. DVD copies available or can be viewed at youtube.com/cftrust.

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