

Cystic Fibrosis Trust

Information resources 2025/26

Published April 2025



Uniting for a life unlimited

Our information



Cystic Fibrosis Trust has been awarded the PIF TICK – the UK's only assessed quality mark for print and online health and care information. All of our information is written and reviewed by experienced CF health professionals and our information team, as well as members of the CF community.

Our information resources are free, but we would be very grateful if you would consider donating to help us continue our important work. You can donate online at cysticfibrosis.org.uk/donate

Trusted
Information
Creator



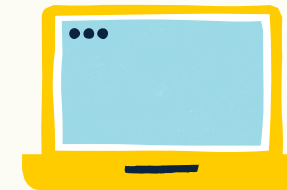
Patient Information Forum

Find out more by visiting our website
cysticfibrosis.org.uk/piftick



How to get our information

We update our information regularly, so our website is the best place to find the most up-to-date information. This also helps us save money on printing and postage costs.



Browse our online content and download our information resources from our website
cysticfibrosis.org.uk/information



Watch our videos
youtube.com/cftrust

Order printed copies by contacting our **Helpline**

- Call **0300 373 1000** or **020 3795 2184**, Monday–Friday 10am–4pm
- Email helpline@cysticfibrosis.org.uk
- Chat with us on **Facebook** and **Instagram**
- Message us on **WhatsApp** on **07361 582053**



Tell us what you think

If you have any comments or feedback on any of our information resources, please share them with us by emailing infoteam@cysticfibrosis.org.uk. We'd love to hear from you!

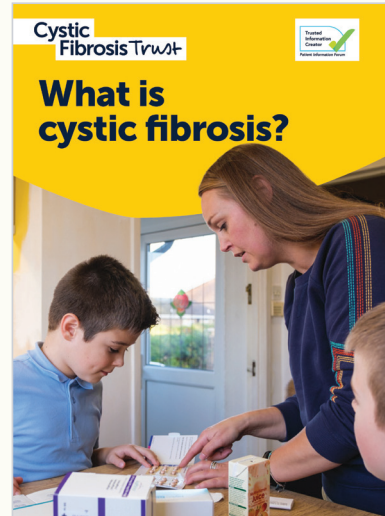
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About cystic fibrosis

Cystic fibrosis is a genetic condition affecting more than **11,000** people in the UK. These resources help to explain what CF is, how it affects those living with it and what's available to support you through any challenges you might be facing.



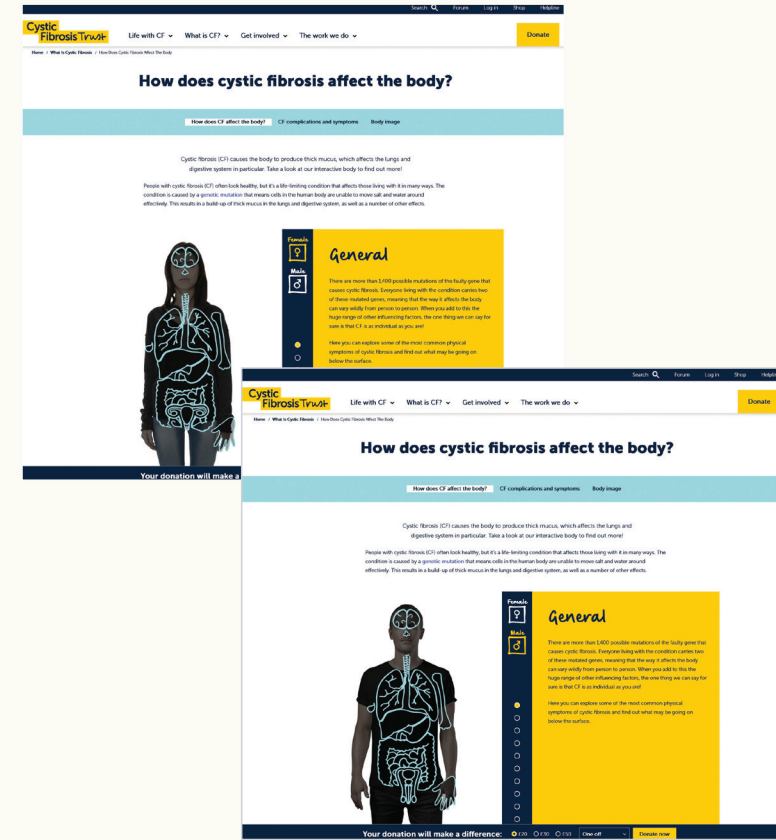
What is cystic fibrosis? leaflet. 2025



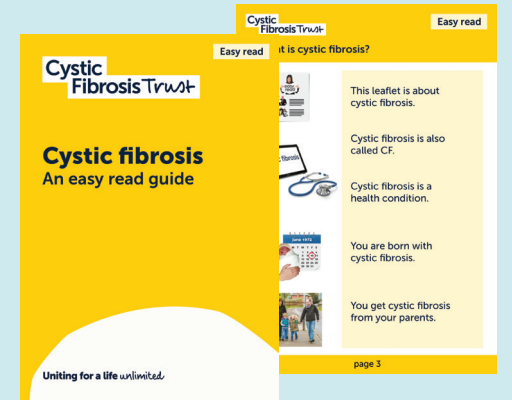
Support for all flyer. 2022



CF Connect flyer. 2022



How does CF affect the body?
cysticfibrosis.org.uk/body



An easy read guide about
cystic fibrosis. 2023
cysticfibrosis.org.uk/easyread



Other resources available

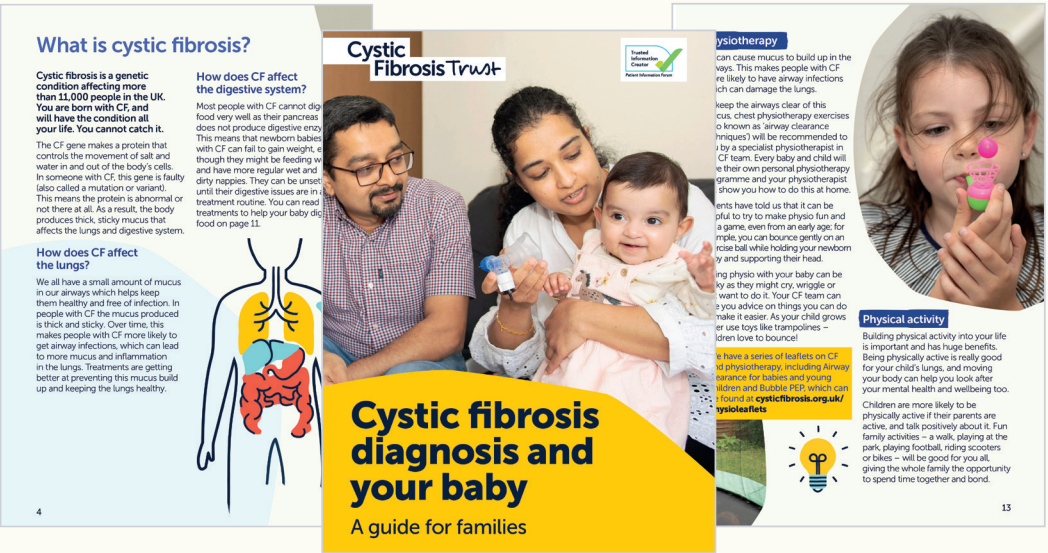
- Cystic fibrosis and cross-infection
cysticfibrosis.org.uk/crossinfection
- Symptoms of cystic fibrosis
cysticfibrosis.org.uk/symptoms

After a diagnosis

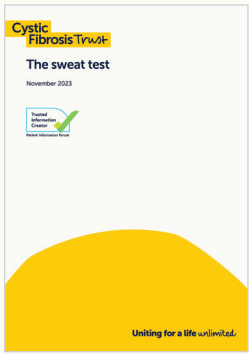
We know how overwhelming it can be if you, your child or someone close to you has just been diagnosed with cystic fibrosis. We've created the following publications to help support you through your journey, and you can also visit cysticfibrosis.org.uk/newdiagnosis to explore some extra resources.



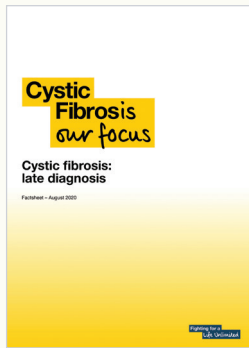
Sign up to receive emails with information to support you throughout your baby's first year
cysticfibrosis.org.uk/newdiagnosisemails



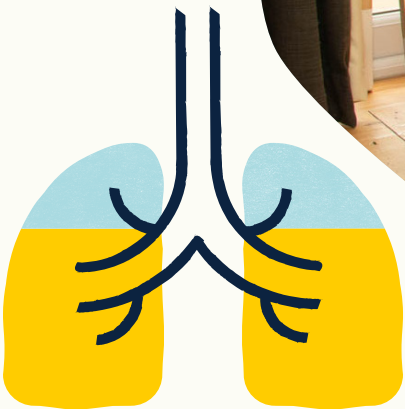
Cystic fibrosis diagnosis and your baby. 2024



The sweat test. 2023



Late diagnosis. 2020



Visit our website to watch films of families' experiences of diagnosis cysticfibrosis.org.uk/newdiagnosis

Living well with cystic fibrosis



These resources look at ways of improving health and wellbeing, eating well, staying active and living a full life with CF.



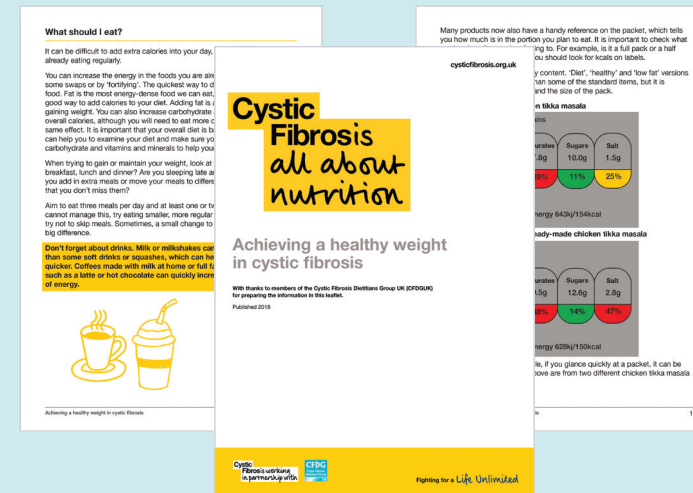
Body image and cystic fibrosis. 2019

Other resources available

- Festival planning guide for young people. 2017
cysticfibrosis.org.uk/festivals
- Growing older with cystic fibrosis
cysticfibrosis.org.uk/growingolder
- Menopause and CF: Let's talk about it!
cysticfibrosis.org.uk/menopause
- Mindfulness exercises
cysticfibrosis.org.uk/mindfulness
- Staying active
cysticfibrosis.org.uk/stayingactive
- Vaping and cystic fibrosis
cysticfibrosis.org.uk/vaping
- Staying safe in hot weather
cysticfibrosis.org.uk/hotweather
- Staying well over winter
cysticfibrosis.org.uk/coldweather

Nutrition

All our nutrition resources are available to download at cysticfibrosis.org.uk/nutritionleaflets



Achieving a healthy weight in cystic fibrosis. 2018

Other resources available

- Exercise nutrition in cystic fibrosis. 2025
- Healthy eating and cystic fibrosis. 2019
- Fasting during Ramadan and cystic fibrosis. 2025. Online only.
- Leaving home and eating well with cystic fibrosis. 2018
- Iron in the cystic fibrosis diet. 2025
- Vitamin supplements in cystic fibrosis. 2025

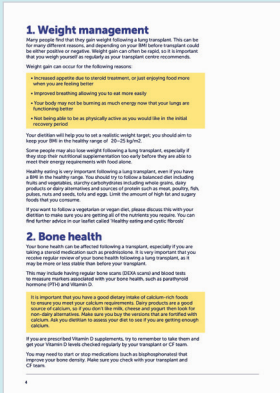
Updates coming soon!

- Gastrointestinal issues in cystic fibrosis. 2020
- Drinking alcohol and cystic fibrosis. 2018
- Calcium and bone health in cystic fibrosis. 2019





Post-lung transplant nutrition for people with cystic fibrosis. 2025



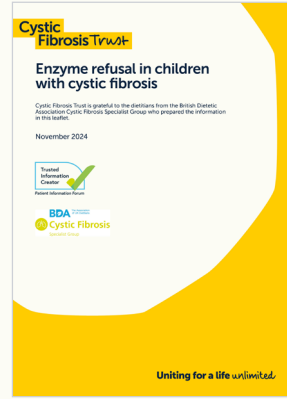
Updates coming soon!

- Pancreatic sufficiency and nutrition in cystic fibrosis (babies) leaflet. 2019
- Pancreatic enzyme supplements and cystic fibrosis. 2020
- Eating well for children with cystic fibrosis, 2019
- Pancreatic insufficiency and nutrition in cystic fibrosis (babies), 2019.
- Weaning information for babies with cystic fibrosis, 2019.

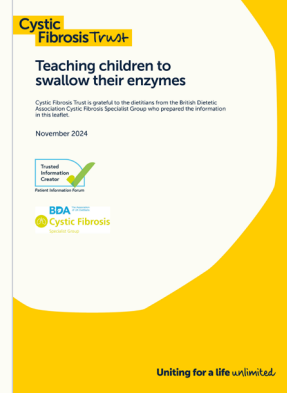


Other resources available

- Salt in the cystic fibrosis diet. 2025
- Staying hydrated and cystic fibrosis. 2025



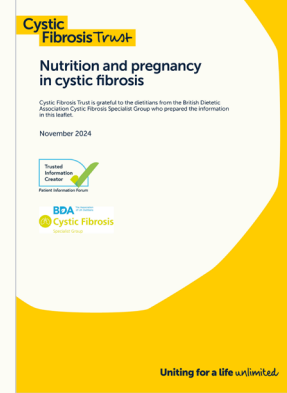
Enzyme refusal in children with cystic fibrosis. 2025



Teaching children to swallow their enzymes. 2025



Food refusal in children with cystic fibrosis. 2025



Nutrition and pregnancy in cystic fibrosis. 2025



Family planning

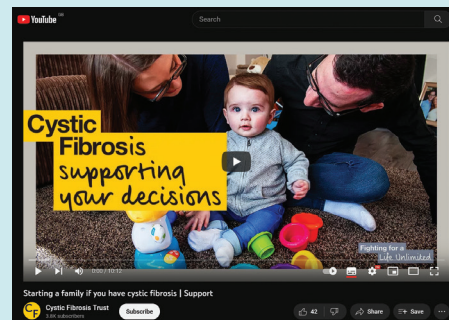
Our information and real stories will help you make informed decisions about starting a family, so that you can feel confident you're making the right choices for your health and your family.



Update coming soon!



Thinking of starting a family? A guide for adults with cystic fibrosis and their partners. 2016



Starting a family if you have cystic fibrosis, featuring two families and a CF doctor answering some questions on fertility and cystic fibrosis

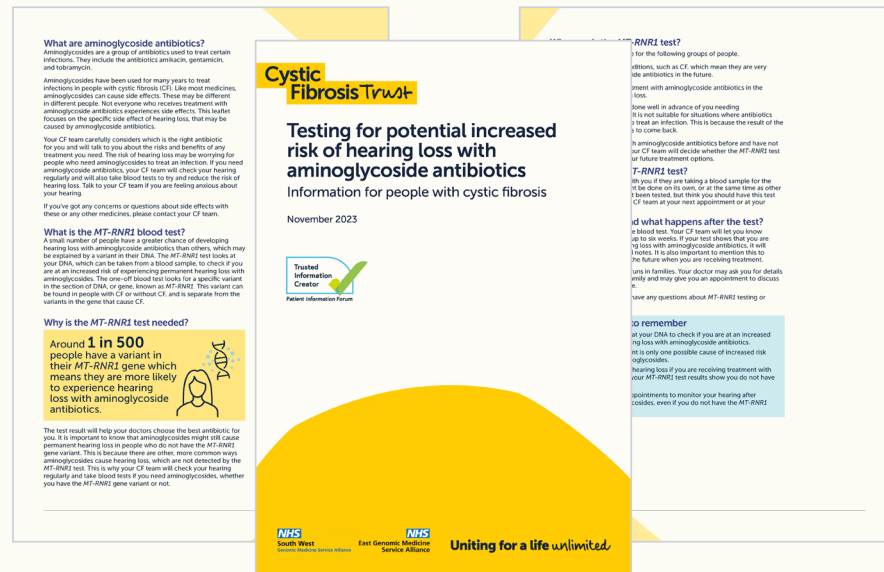
Other resources available

- **Testing for cystic fibrosis carriers in families. 2024**
- **Carrier testing GP letter. 2023**
cysticfibrosis.org.uk/carriertesting
Online only.



Treatments, therapies and care

Thanks to breakthroughs in CF treatment, people with CF are living longer and healthier lives than ever before. Please speak to your CF team before making any changes to your treatment regime.



Testing for potential increased risk of hearing loss with aminoglyco side antibiotics. 2023. Online only.



My portacath – Information on ports for people with cystic fibrosis. 2022



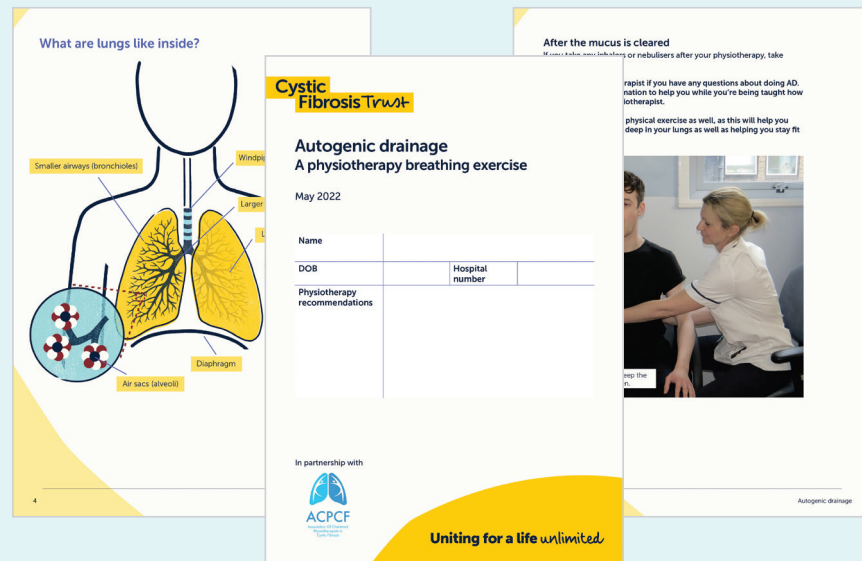
Other resources available

- Home intravenous therapy. 2022
- Inhaled therapy for people with cystic fibrosis. 2023
- The use of ports in cystic fibrosis. 2022

Updates coming soon!

- Kaftrio – complex and individual experiences. 2022. Online only. cysticfibrosis.org.uk/factsheets
- Steroid treatment in cystic fibrosis. 2015

Physiotherapy and lung health



Autogenic drainage (AD). 2022

Other resources available

- Bubble PEP. 2018
- Airway clearance plan. 2022
- Active cycles of breathing technique. 2018
- Airway clearance for babies and young children with cystic fibrosis. 2021
- How to use your PEP Mask. 2018
- How to improve your posture. 2018
- PARI PEP™. 2018
- Keeping your lungs healthy. 2022 cysticfibrosis.org.uk/physioleaflets
- Pelvic floor exercises (female). 2018

Updates coming soon!

- The Acapella® choice. 2018
- Non-tuberculous mycobacteria (NTM) in cystic fibrosis. 2023 cysticfibrosis.org.uk/factsheets

Have a look at our series of physiotherapy 'how-to' videos cysticfibrosis.org.uk/physiovideos

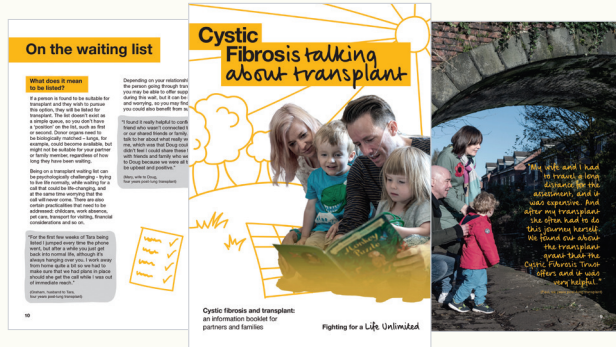


Coming soon!

Why do I wee when I cough or sneeze?
Leaflets for parents and carers, and for children and young people, about stress incontinence and pelvic floor exercises.



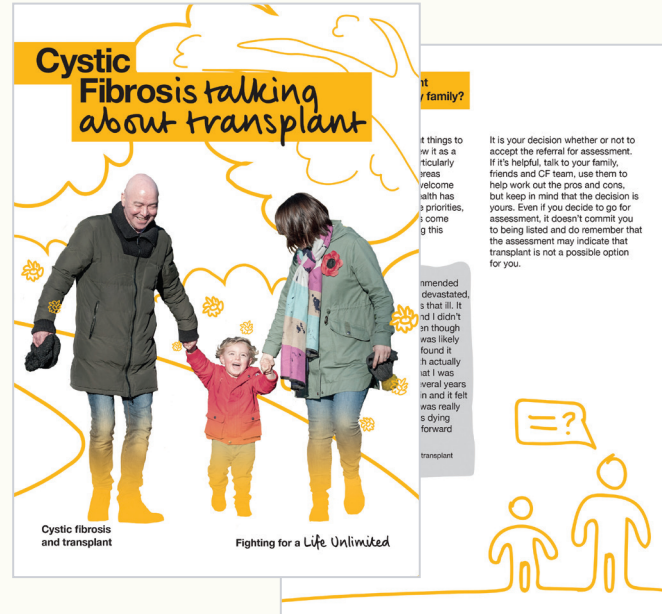
Transplants



Cystic fibrosis and transplant: An information booklet for partners and families. 2018



Cystic fibrosis and lung transplant: An information booklet for parents. 2018



Cystic fibrosis and transplant. 2018

Taking part in clinical trials

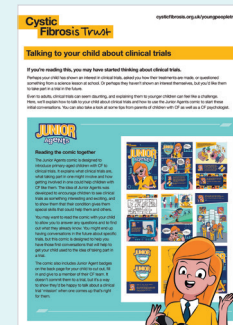
The Junior Agents comic is for primary-age children with CF to introduce them to the concept of clinical trials. Junior Agents comic. 2020



Clinical trials resource for parents of young children. 2020



An introduction to taking part in clinical trials. 2024



Clinical trials resource for young people. 2020



Could you change the future of cystic fibrosis? cysticfibrosis.org.uk/youngpeopletrials

Transitioning from paediatric to adult CF care

Visit cysticfibrosis.org.uk/transition to find out more.

Your transition to adult care:
A guide for young people. 2020

This pack comes in a presentational folder, and includes:

- A transition booklet
- Tips and ideas for a smooth transition
- Questions to ask your old and new teams
- A transition checklist
- My adult CF team template



Transition to adult care: A guide for families and carers booklet. 2020

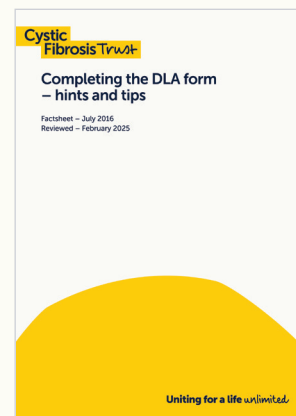


Money and benefits



We have information on benefits, like Disability Living Allowance (DLA) and Personal Independence Payment (PIP), and other financial support you may be eligible for. Visit cysticfibrosis.org.uk/financialsupport for information about all of the financial support we offer.

Need help with applying for benefits? We can support you through the process. To find out more, contact our Helpline on **0300 373 1000** or email helpline@cysticfibrosis.org.uk



Completing the DLA form:
Hints and tips. 2024
cysticfibrosis.org.uk/DLA

Other resources available

- Prescription charges for cystic fibrosis
cysticfibrosis.org.uk/prescriptions
- Personal Independence Payment (PIP) for those aged 16+
cysticfibrosis.org.uk/PIP
- Universal credit (UC)
cysticfibrosis.org.uk/universalcredit

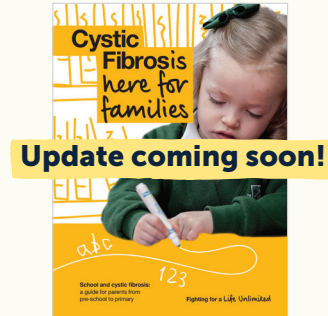
“We provide information resources and expert advice to help you understand the benefits system and access any support you are entitled to.”

Sangeeta Enright – Welfare and Rights Advisor, Cystic Fibrosis Trust



Sangeeta Enright – Welfare & Rights Advisor, Cystic Fibrosis Trust

Education and work



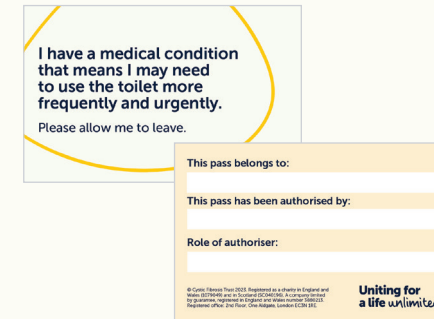
School and cystic fibrosis: A guide for parents from pre-school to primary. 2016



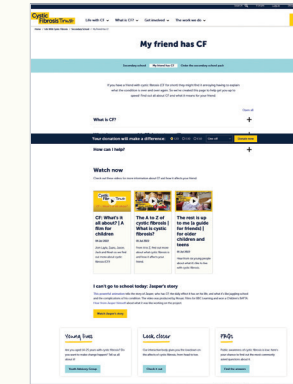
Primary school pack: For school staff. 2016



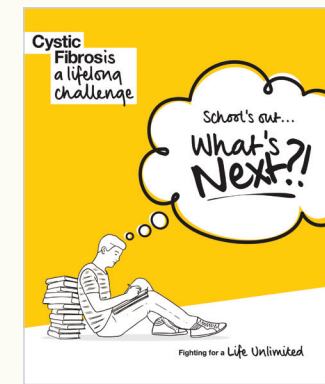
Individual healthcare plan for preschools and primary schools. 2020



Class passes. 2023. We have seven passes to choose from, for if you need to move seat, or leave class to cough or go to the toilet.



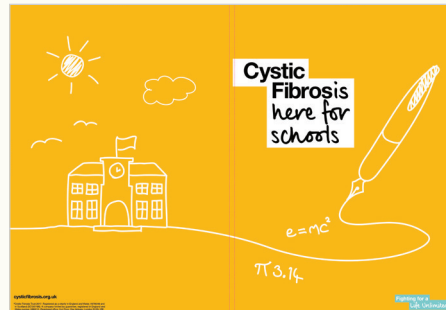
My friend has CF cysticfibrosis.org.uk/friend



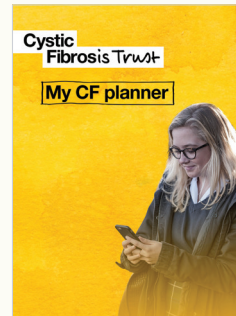
Schools out...what's next?! 2018



Starting secondary school: Booklet for parents. 2017



Secondary school pack: For school staff. 2021



My CF planner: An individual healthcare plan. 2020



Support your child's next step. 2018

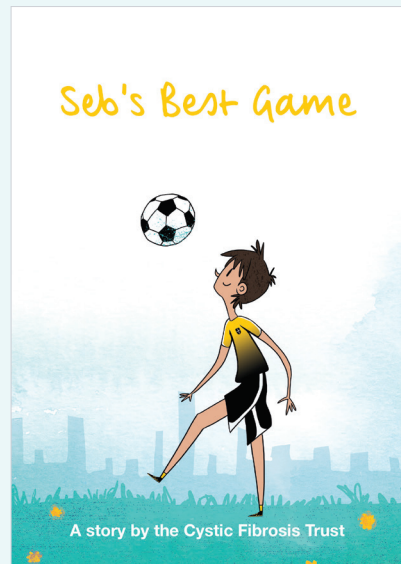


Information for training providers, colleges and universities. 2018 cysticfibrosis.org.uk/leavingschool

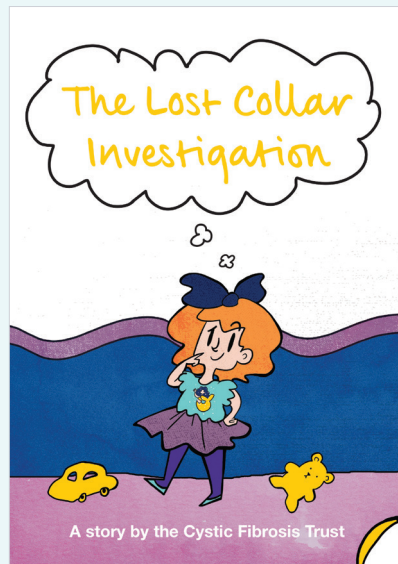


You can find information and support on work and careers at cysticfibrosis.org.uk/workforwards

Resources for children

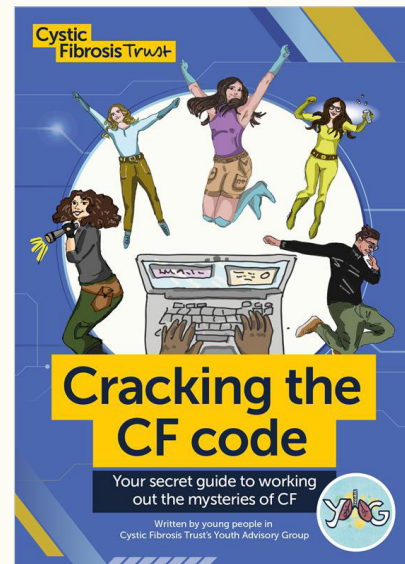


Seb's Best Game
Children's book. 2018



The Lost Collar Investigation
Children's book. 2018

Our two children's books are written for children who have a parent with cystic fibrosis. You can also watch animated versions of both books and download PDF versions at cysticfibrosis.org.uk/rosieandseb



Cracking the CF code. 2025
A dictionary of CF terms for children aged 6–9, written by young people in our Youth Advisory Group.



Noah, 8

Jack, 3



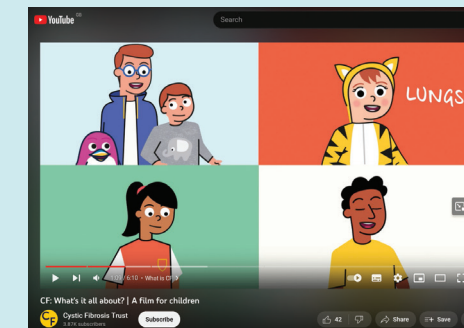
Jason, 10



Zaara, 11



Huffin



Watch our video
CF: What's it all about? 2022

CF: What's it all about?
Children's activity pack. 2022

Cystic fibrosis-related conditions



Cystic fibrosis affects many different parts of the body, and people with CF can experience a wide range of symptoms and related conditions. Our information explains how these conditions can be diagnosed and managed.

Find out more about some of the other symptoms that come with cystic fibrosis by visiting cysticfibrosis.org.uk/symptoms



Cystic fibrosis diabetes. 2023

Other resources available

- Additional symptoms of cystic fibrosis cysticfibrosis.org.uk/symptoms
Online only.

Updates coming soon!

- Melioidosis and worldwide travel. 2017
- Cystic fibrosis-related liver disease. 2017
- Cystic fibrosis and bone health. 2020



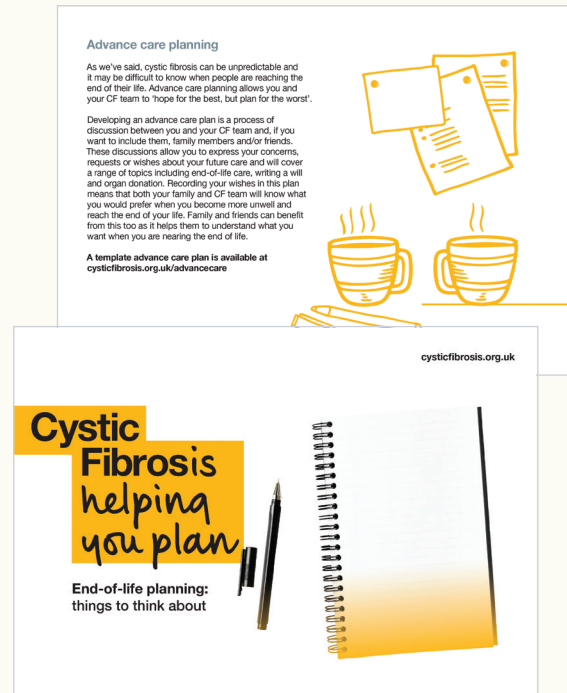
End-of-life planning



Making plans for the end of life can be difficult, but it's a good idea for everyone to start thinking about it early on, whether they have a condition that affects their health or not.



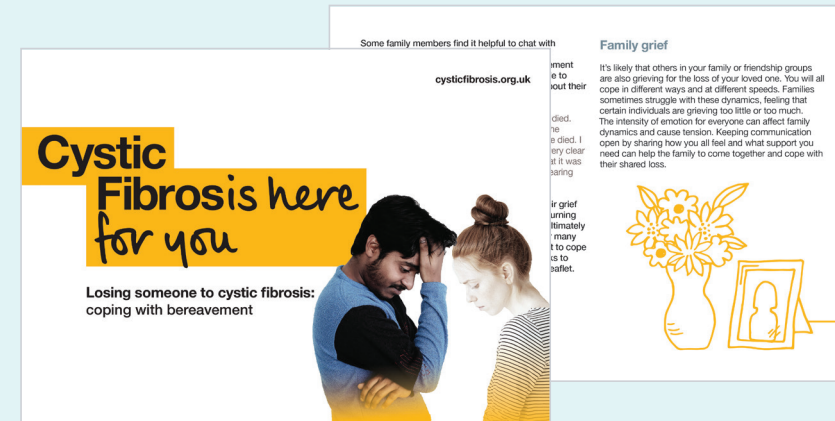
Advanced care planning form, available at cysticfibrosis.org.uk/planningahead



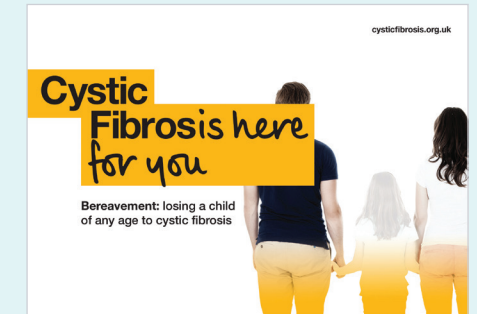
End-of-life planning. 2017

Bereavement

Coping with the death of someone close to you can be one of the hardest things we ever have to deal with. Our bereavement resources can help to support you to cope with that loss. While we can't offer specialist bereavement counselling, our **Helpline** can provide a listening ear and direct you to further sources of support.



Coping with bereavement. 2017



Losing a child of any age to cystic fibrosis. 2017



Supporting a child bereaved through cystic fibrosis. 2017

Support for the CF community



Our resources are just one part of the information and support we offer to people with CF and their families.

Cystic Fibrosis Trust Helpline

Our Helpline is open 10am–4pm Monday to Friday. It's available to anyone looking for information or support with any part of cystic fibrosis, a listening ear, or just to talk things through.

You can contact our friendly team by:

- phoning 0300 373 1000 or 020 3795 2184
If you are worried about the cost of the call please let us know and we'll call you back.
- messaging us on **WhatsApp**, on **07361 582053**
- emailing **helpline@cysticfibrosis.org.uk**
- reaching out on all our social media channels

Visit **cysticfibrosis.org.uk/helpline** for more information.

Cystic Fibrosis Community

Join our online forum where people affected by CF can share experiences, connect, and support each other in a safe, private space. The forum is divided into a wide range of topics, which makes it easier to find the discussions you are interested in, while avoiding those you would rather not be a part of.

Visit **forum.cysticfibrosis.org.uk** to join.

Benefits advice

We understand it can be complicated to navigate the benefits system. Find out how we can support you through the process by visiting **cysticfibrosis.org.uk/benefits** or by contacting our Helpline.

Income maximisation

Our Income Maximisation Service can support you to make sure you are getting all the financial assistance you are entitled to, and help you to make the most out of your money. Contact our Helpline to access this service.

If you're a student, we can give personalised support through our Student Support Service to help you maximise your income, including looking at benefits and budgeting. Get in touch with our Helpline to find out more.

Grants

We offer grants to support people with CF and their families through challenging times.

Visit **cysticfibrosis.org.uk/grants** to find out more.

CF Connect

Our CF Connect service puts parents, relatives and friends in touch with trained volunteers who also have a child with CF, so that experiences and advice can be shared in confidence. Access CF Connect by contacting the Helpline. Find out more at **cysticfibrosis.org.uk/cfconnect**

Support for young people

We run fun and exciting online events for children, so they can make friends, have fun and learn new skills. From games nights and free online workshops to movie nights, we have something for everyone!

Find out more at **cysticfibrosis.org.uk/cfyouth**

Work Forwards

Work Forwards is our programme of free tailored careers information, advice, and guidance for people with CF and their loved ones.

Find out more at **cysticfibrosis.org.uk/workforwards**



Take a look at our magazine, CF Life, at **cysticfibrosis.org.uk/cflife**

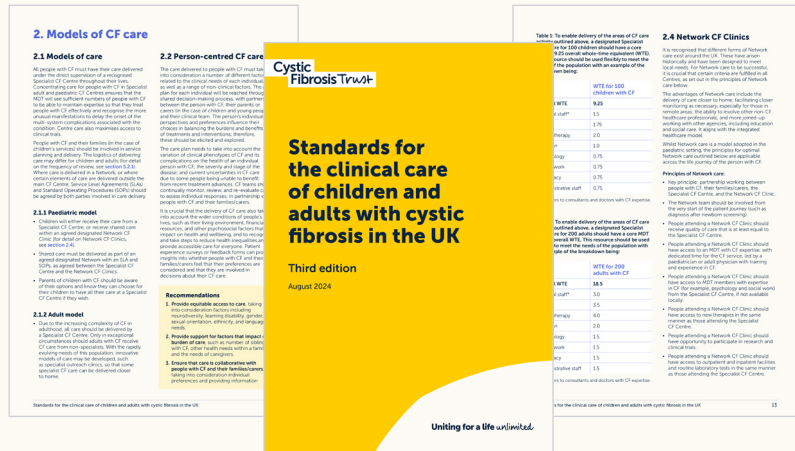
Listen to our podcast, CForYourself, at **cysticfibrosis.org.uk/podcast** or wherever you get your podcasts.

Sign up to our newsletter, CF News, at **cysticfibrosis.org.uk/newsletter** or our dedicated e-newsletter for professionals at **cysticfibrosis.org.uk/cfpros**

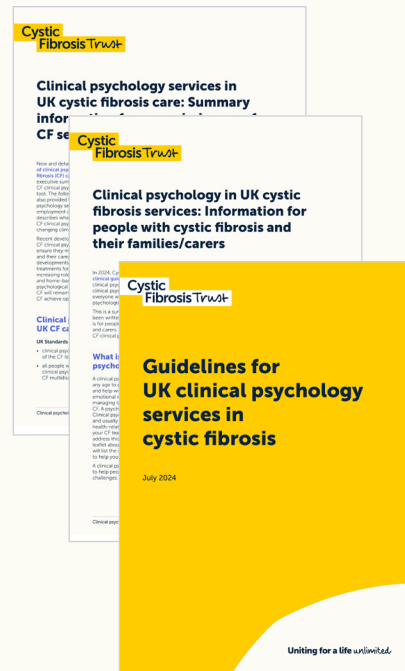
Resources for professionals



To ensure those with CF receive the best possible care and treatment, we've developed consensus documents outlining the standards of care we expect from CF clinicians and other CF health professionals. These documents are written by doctors, health professionals and scientists in a range of specialist areas, and give guidance in key and emerging areas of CF care and treatment. Our consensus documents are available online only from cysticfibrosis.org.uk/consensus



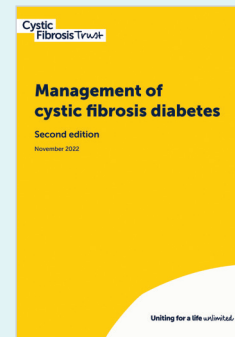
Standards for the clinical care of children and adults with cystic fibrosis in the UK. 2024. Read the lay summary at cysticfibrosis.org.uk/standardsofcare



Guidelines for UK clinical psychology services in cystic fibrosis. 2024
Lay summary for people with CF
Lay summary for commissioners and clinical directors



National consensus standards for the nursing management of cystic fibrosis. 2025



Management of cystic fibrosis diabetes. 2022

Other resources available

- Nutritional management of cystic fibrosis. 2016
- Pharmacy standards of care. 2022
- European cystic fibrosis bone mineralisation guidelines. 2011
- Advanced care planning guidance for clinicians, 2017. PDF only, available to download from cysticfibrosis.org.uk/planningahead
- Laboratory standards for processing microbiological samples from people with cystic fibrosis. 2022

Under review!

- Standards of care and good clinical practice for the physiotherapy management of cystic fibrosis. 2020
- Antibiotic treatment for cystic fibrosis. 2009
- NTM guidelines. 2017 (amended March 2018)
- Methicillin-resistant *Staphylococcus aureus* (MRSA). 2008
- *Pseudomonas aeruginosa* infection in people with cystic fibrosis: Suggestions for prevention and infection control. 2004
- The *Burkholderia cepacia* complex: Suggestions for prevention and infection control. 2004

How can you get involved?



Supporters of Cystic Fibrosis Trust generously donate their time, money and voices to help us work towards a life unlimited by cystic fibrosis. There are lots of ways you can help.

Take a look at cysticfibrosis.org.uk/getinvolved for more information on getting involved with the Trust.



Organise a fundraising event



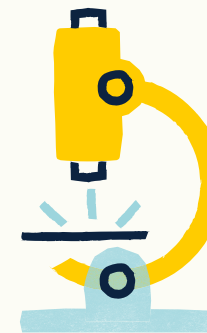
Make a donation



Get sponsored for an event



Lend your voice to our **campaigns** and raise awareness of the condition



Join our **Involvement group** to help influence the work of the Trust, researchers, and clinicians.



Join our **Youth Advisory Group** if you're aged 14–25.

Cystic Fibrosis Trust

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

Visit **cysticfibrosis.org.uk** to find out more about cystic fibrosis.

Search Cystic Fibrosis Trust

Find us online, on social media, and wherever you get your podcasts.



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Uniting for a life *unlimited*