Cystic Fibrosis Trust

Information resources 2023/24

Published September 2023

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.

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, Twitter or Instagram**
- Message us on **WhatsApp** on **07361 582053**

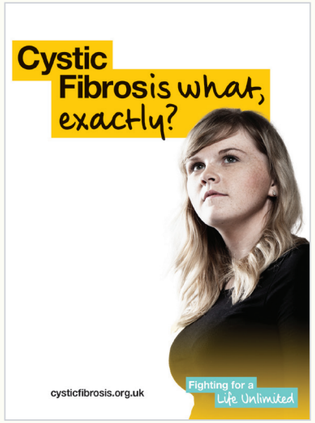
Tell us what you think

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!

Contents

About cystic fibrosis

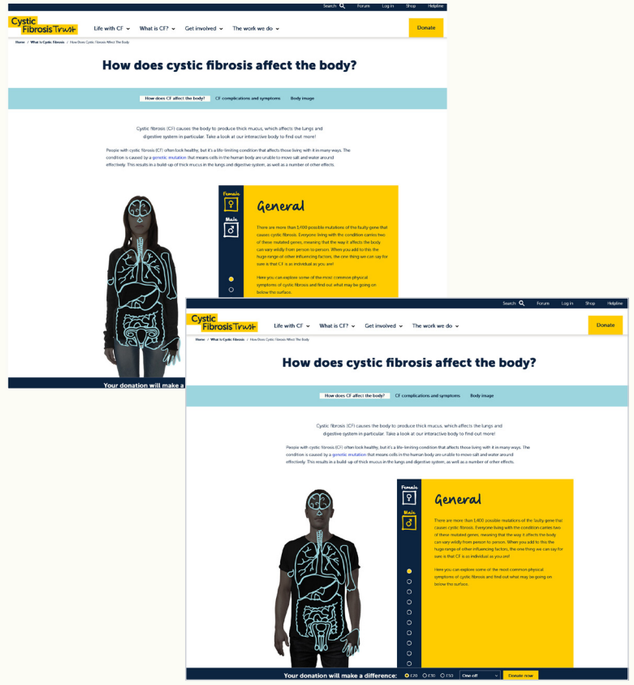
Cystic fibrosis is a genetic condition affecting more than **10,900** people in the UK. These resources help to explain what CF is, how it affects those living with it and what's available to support you through any challenges you might be facing.



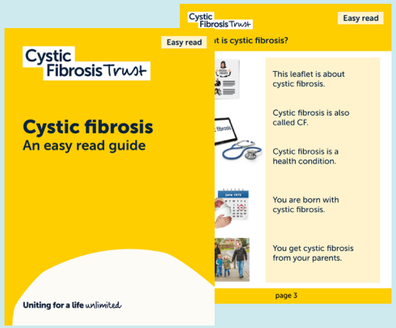
Cystic fibrosis is what exactly? 2019.
Order code: CFLEAFLET

Support for all flyer 2022.
Order code: CFSUPPORTLFLT

CF Connect flyer 2022.
Order code: CFCONNECTLFLT



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



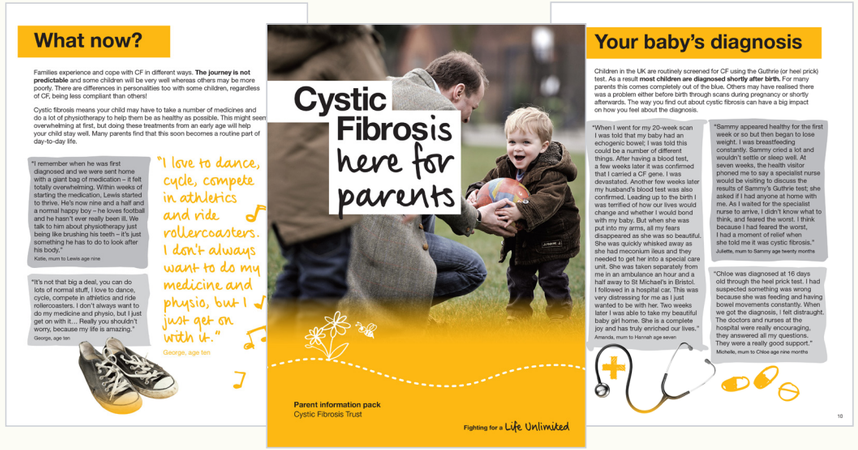
An easy read guide about cystic fibrosis, 2023.
Order code: CFEASYREADGUID
cysticfibrosis.org.uk/easyread

Other information available

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

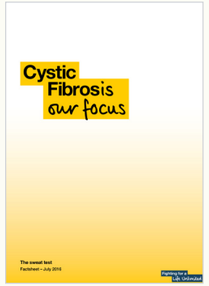
After a diagnosis

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.

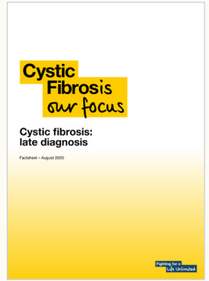


Update coming soon!

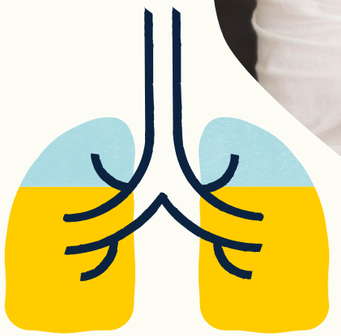
Parent information pack, including the friends and family guide leaflets. 2015.
Order code: CFPARENTPACK



The sweat test, 2016.
Order code: CFSWEAT



Late diagnosis, 2020.
Order code: CFADULTHOOD



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

Living well with cystic fibrosis

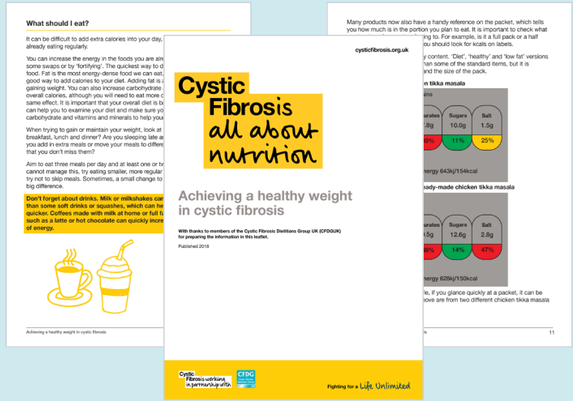
These resources look at ways of improving health and wellbeing, eating well, staying active and living a full life with CF.

Body image and cystic fibrosis, 2019.
Order code: CFBODYIMAGE

Other information 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**

Exercise and nutrition



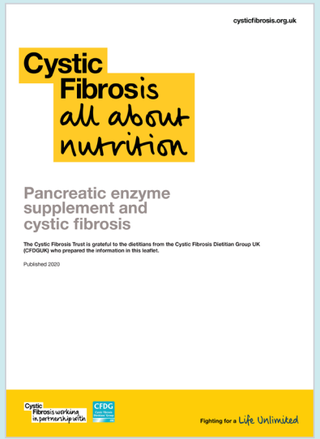
Achieving a healthy weight in cystic fibrosis, 2018.
Order code: CFNUWEIGHT

These factsheets come as one pack

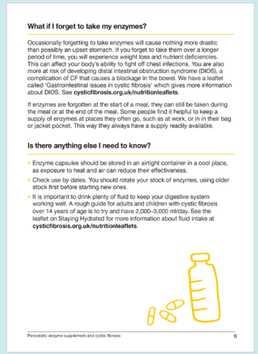
Calcium and bone health in cystic fibrosis, 2019.
Iron in the cystic fibrosis diet, 2019.
Vitamin supplements in cystic fibrosis, 2019.
Order code: CFNUVITS

Other information available

- **Exercise nutrition in cystic fibrosis**, 2018. Order code: CFNUEXERCISE
- **Healthy eating and cystic fibrosis**, 2019. Order code: CFNUHEALTHY
- **Gastrointestinal issues in cystic fibrosis**, 2020. Order code: CFNUGIISSUES
- **Drinking alcohol and cystic fibrosis**, 2018. Order code: CFNUALCOHOL
- **Fasting during Ramadan and cystic fibrosis**, 2021. **cysticfibrosis.org.uk/ramadan**
- **Leaving home and eating well with cystic fibrosis**, 2018. Order code: CFNULEAVE



Pancreatic enzyme supplements and cystic fibrosis, 2020.
Order code: CFNUENZYME



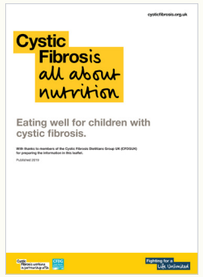
Other information available

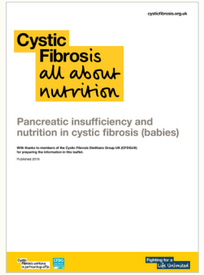
- **Pancreatic sufficiency and nutrition in cystic fibrosis (babies)** leaflet, 2019.
  Download from **cysticfibrosis.org.uk/nutritionleaflets**
- **Post-lung transplant nutrition for people with cystic fibrosis**, 2019.
  Order code: CFNUPOSTLUNG

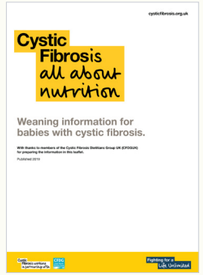
These factsheets come as one pack

Salt in the cystic fibrosis diet, 2019.
Staying hydrated and cystic fibrosis, 2019.
Order code: CFNUHYDSALT

These factsheets come as one pack







Eating well for children with cystic fibrosis, 2019

Pancreatic insufficiency and nutrition in cystic fibrosis (babies), 2019.
Download separately from **cysticfibrosis.org.uk/nutritionleaflets**

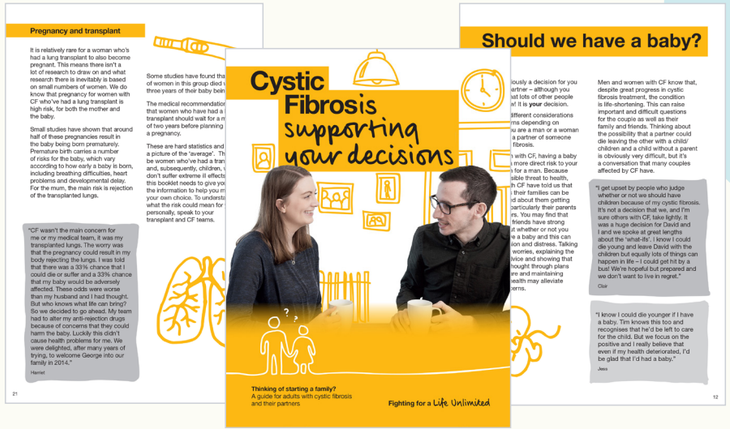
Weaning information for babies with cystic fibrosis, 2019.
Order code: CFNUPAED1

Other information available

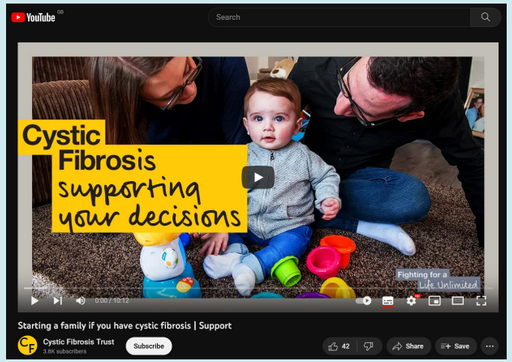
- **Enzyme refusal in children with cystic fibrosis**, 2020.
  Order code: CFNUENZREF
- **Food refusal in children with cystic fibrosis**, 2019.
  Order code: CFNUFOODREF
- **Learning to swallow enzymes for children with cystic fibrosis**, 2020.
  Order code: CFNUSWALLOW
- **Nutrition and pregnancy in cystic fibrosis leaflet**, 2018.
  Order code: CFNUPREG

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.



Thinking of starting a family? A guide for adults with cystic fibrosis and their partners, 2016.
Order code: CFFERTBOOK



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

Other information available

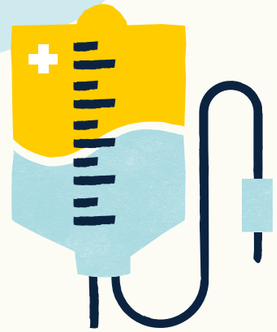
- **Testing for cystic fibrosis carriers in families,** 2022.
  Order code: CFCASCADE

Treatments, therapies and care

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

Kaftrio – complex and individual experiences, 2022.
cysticfibrosis.org.uk/factsheets

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



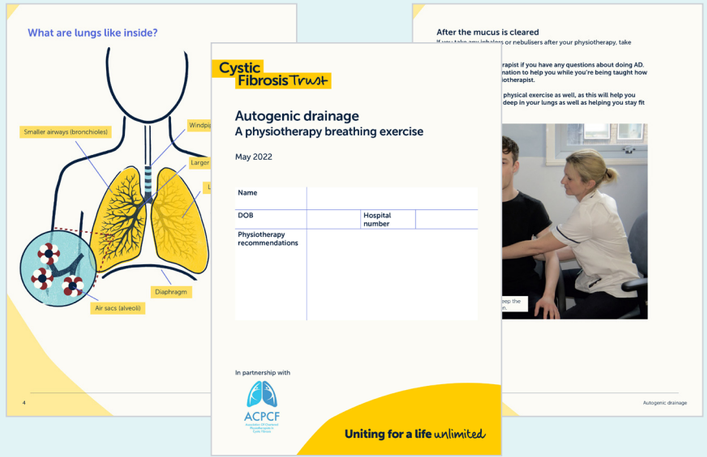
Other information available

- **Steroid treatment in cystic fibrosis**, 2015.
  Order code: CFSTEROID

Update coming soon!

- **Home intravenous therapy**, 2022.
  Order code: CFHOMEIV
- **Inhaled therapy for people with cystic fibrosis**, 2023.
  Order code: CFINHALED
- **The use of ports in cystic fibrosis**, 2022.
  Order code: CFPORTACATH

Physiotherapy and lung health



Autogenic drainage (AD), 2022.
Order code: CFAUTO

Other information available

- **Bubble PEP**, 2018.
  Order code: CFBUBBLE
- **Airway clearance plan**, 2022.
  Order code: CFACP
- **Active cycles of breathing technique**, 2018.
  Order code: CFACBT
- **Airway clearance for babies and young children with cystic fibrosis**, 2021.
  Order code: CFAIRWAY
- **How to improve your posture**, 2018.
  Order code: CFPOSTURE

Update coming soon!

- **The Acapella® choice**, 2018.
  Order code: CFACAPELLA
- **How to use your PEP Mask**, 2018.
  Order code: CFPEP
- **PARI PEP™**, 2018.
  Order code: CFPARI
- **Keeping your lungs healthy**, 2022.
  cysticfibrosis.org.uk/physioleaflets
- **Pelvic floor exercises (female)**, 2018.
  Order code: CFPELVIC

Update coming soon!

- **Non-tuberculous mycobacteria (NTM) in cystic fibrosis,** 2023
  cysticfibrosis.org.uk/factsheets

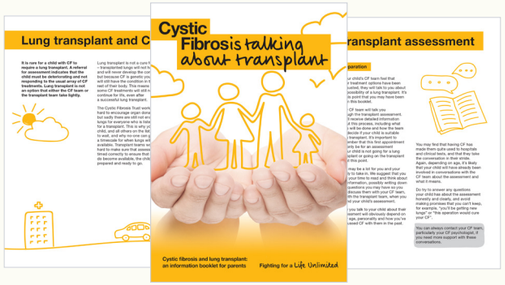
Coming soon!

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.

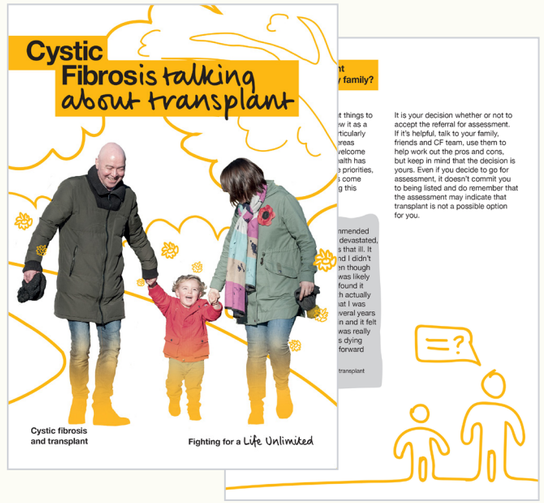
Pelvic floor exercises (male)

Transplants

Cystic fibrosis and transplant: An information booklet for partners and families, 2018. Order code: CFTRANSBKPF



Cystic fibrosis and lung transplant: An information booklet for parents, 2018. Order code: CFTRANSBKP



Cystic fibrosis and transplant, 2018. Order code: CFTRANSBOOK

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. Order code: CFCYPCOMIC

Update coming soon!

Taking part in clinical trials: A guide for people with cystic fibrosis, parents and family members, 2017. Order code: CFTRIALSBOOK

Clinical trials resource for parents of young children, 2020. Order code: CFCYPRESPAR

Use these together!

Clinical trials resource for young people, 2020. Order code: CFCYPRESYP

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

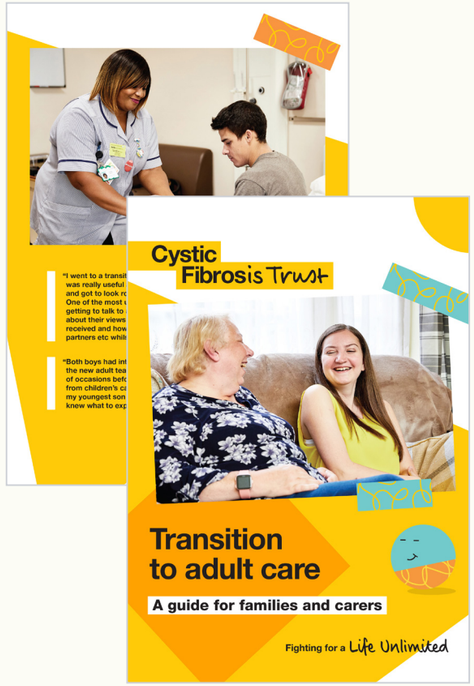
Transitioning from paediatric to adult CF care

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

Order code: CFTRANSYP



Transition to adult care: A guide for families and carers booklet, 2020. Order code: CFTRANSBK

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**

Sangeeta Enright – Welfare & Rights Advisor, Cystic Fibrosis Trust

Completing the DLA form: Hints and tips, 2019.
cysticfibrosis.org.uk/DLA

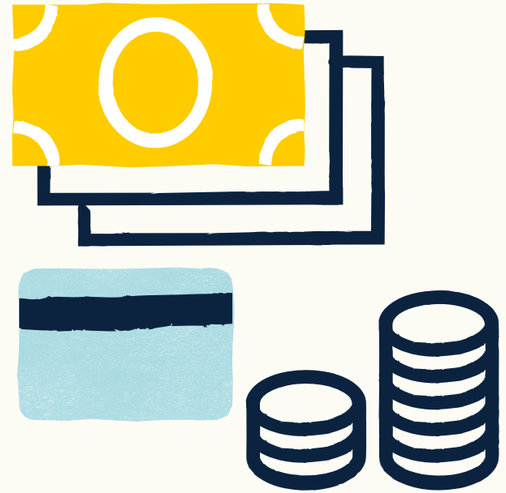
Personal Independence Payment (PIP) for those aged 16+
cysticfibrosis.org.uk/PIP

A guide to the assessment criteria for PIP cysticfibrosis.org.uk/PIPcriteria

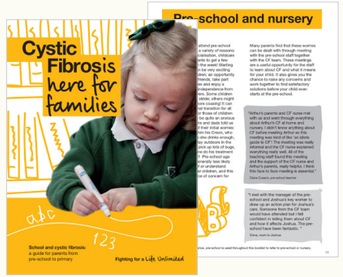
Guidance for PIP: Face-to-face assessments, 2018.
cysticfibrosis.org.uk/PIP

Other information available

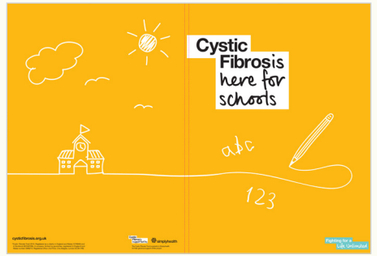
- Prescription charges for cystic fibrosis **cysticfibrosis.org.uk/prescriptions**
- Disability Living Allowance (DLA) for children under 16 **cysticfibrosis.org.uk/DLA**



Education and work



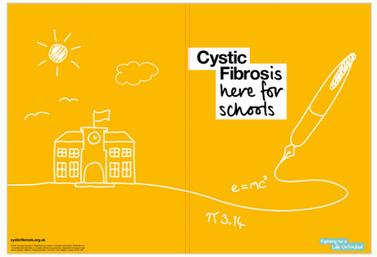
School and cystic fibrosis: A guide for parents from pre-school to primary, 2016.
Order code: CFPSCHBOOK



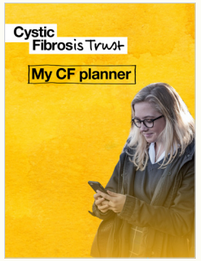
Primary school pack: For school staff, 2016.
Order code: CFPSCHFOLDER
cysticfibrosis.org.uk/school

Starting secondary school: Booklet for parents, 2017.
Order code: CFSSCHBOOK

Starting secondary school magazine for young people, 2017.
Order code: CFSSCHMAG

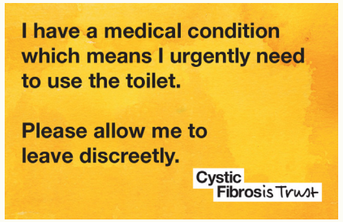


Secondary school pack: For school staff, 2021.
Order code: CFSSCHFOLDER

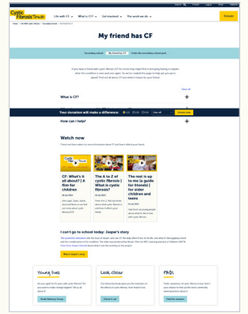


My CF Planner an individual healthcare plan, 2020.
cysticfibrosis.org.uk/secondaryschool

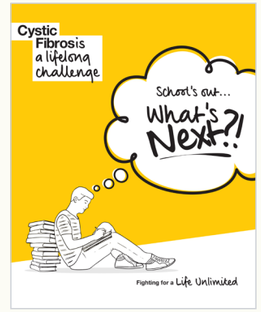
Update coming soon!



Class passes, 2021. if you need to move seat, or leave class to cough or go to the toilet. **cysticfibrosis.org.uk/secondaryschool**



My friend has CF
cysticfibrosis.org.uk/friend



Schools out...what's next?! 2018.
Order code: CFPOST16YP

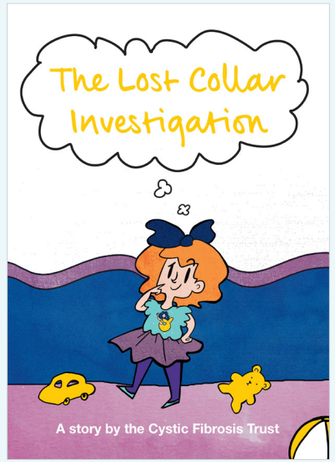
Support your child's next step, 2018.
Order code: CFPOST16P

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

The A–Z of cystic fibrosis

Resources for children

Seb's Best Game hardback children's book, 2018.
Order code: CFKIDSBOOK2



The Lost Collar Investigation hardback children's book, 2018.
Order code: CFKIDSBOOK1

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**

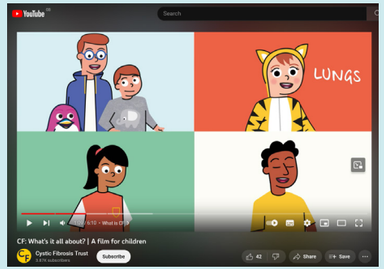
Layla, 7

Noah, 8 Jack, 3

Jason, 10

Zaara, 11

Huffin



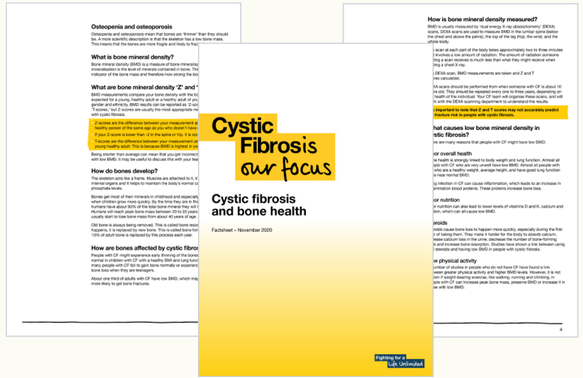
Watch our video
CF: What's it all about, 2022

Children's activity pack, 2022.
Order code: CFCHLDACTIVITY

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 and bone health, 2020.
Order code: CFBONE

Other information available

- **Melioidosis and worldwide travel**, 2017. Order code: CFMEL
- Additional symptoms of cystic fibrosis **cysticfibrosis.org.uk/symptoms**
- **Cystic fibrosis-related diabetes**, 2017. Order code: CFDIABETES

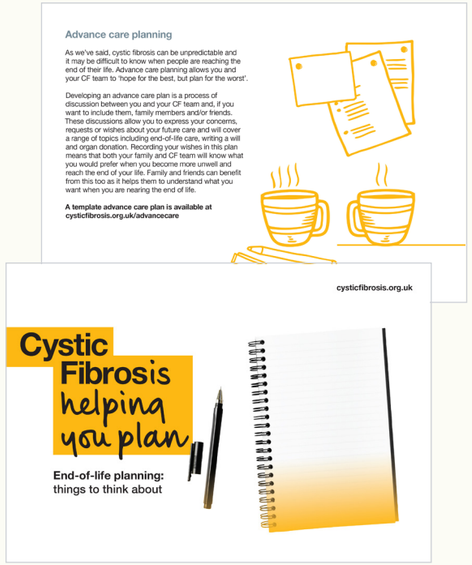
Update coming soon!

- **Cystic fibrosis-related liver disease**, 2017. Order code: CFLIVER

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 for people with CF Interactive online form, available at **cysticfibrosis.org.uk/planningahead**



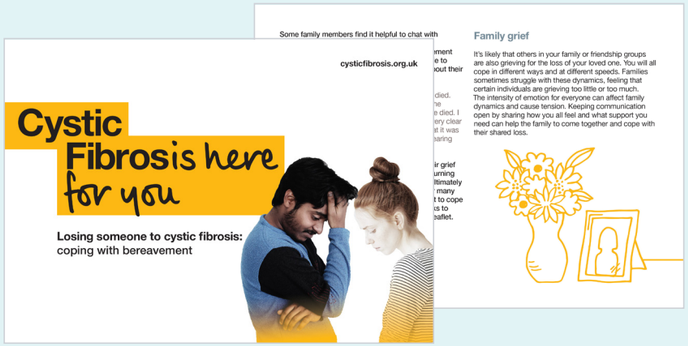
End of life planning booklet, 2017.
Order code: CFEOLBOOK

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.

Call **0300 373 1000** or email **helpline@cysticfibrosis.org.uk**.

We also offer resources for CF professionals on end-of-life care.



Coping with bereavement booklet, 2017. Order code: CFBEREBOOK

Losing a child of any age to CF booklet, 2017.
Order code: CFLOSCHILDBK

Supporting a child bereaved through CF booklet, 2017.
Order code: CFCHILDBERBK

Support for people in the 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

Parents of children with CF often struggle to meet up with each other and can miss out on the opportunity to talk to someone who knows how they feel. 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.

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**

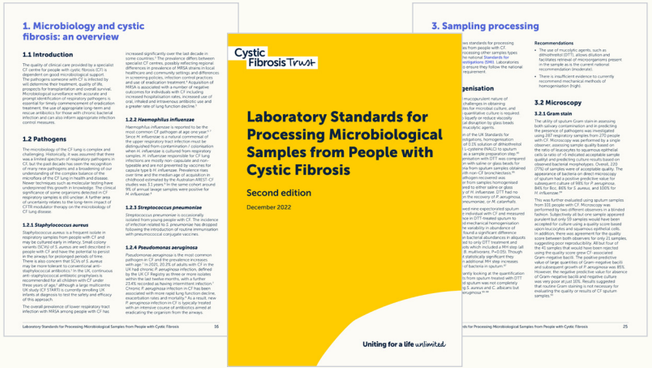
Work Fowards

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

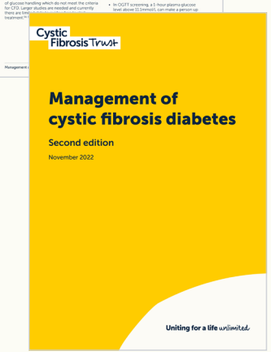
Find out more at **cysticfibrosis.org.uk/life-with-cf/work-forwards**

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**



Laboratory standards for processing microbiological samples from people with cystic fibrosis, 2022



Management of cystic fibrosis diabetes, 2022

Other information available

- **NTM guidelines**, 2017 (amended March 2018)
- **Methicillin-resistant Staphylococcus Aureus (MRSA)**, 2008
- **National consensus standards for the nursing management of cystic fibrosis**, 2001

Under review!

- **Nutritional management of cystic fibrosis**, 2016
- **Pharmacy standards of care**, 2022
- **Pseudomonas aeruginosa infection in people with cystic fibrosis: Suggestions for prevention and infection control**, 2004
- **Standards for the clinical care of children and adults with cystic fibrosis in the UK**, 2011

Under review!

- **Standards of care and good clinical practice for the physiotherapy management of cystic fibrosis**, 2020
- **The Burkholderia Cepacia complex: Suggestions for prevention and infection control**, 2004
- **Advanced care planning guidance for clinicians**, 2017. PDF only, available to download from **cysticfibrosis.org.uk/planningahead**
- **Antibiotic treatment for cystic fibrosis**, 2009

Under review!

- **European cystic fibrosis bone mineralisation guidelines**, 2011

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.

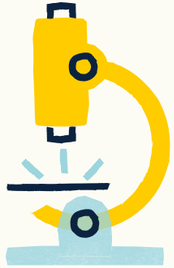
Take a look at **cysticfibrosis.org.uk/getinvolved** for more information on getting involved with the Trust.

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 shape the future of CF research

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 our website **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.

Uniting for a life unlimited