



About us

The Cystic Fibrosis Trust is the only UK-wide charity dedicated to fighting for a life unlimited by cystic fibrosis (CF) for everyone affected by the condition by:

- Investing in cutting-edge research to develop improved treatments.
- Promoting the highest standards of clinical care at specialist CF centres and clinics across the UK.
- Providing trusted information, advice and support to those affected, through our website, resources and support services.
- Campaigning hard on the issues that matter alongside people with CF and their families.

Our information

We offer free, balanced information on all aspects of life with CF, both on our website at cysticfibrosis.org.uk, and in our resources. Along with the medical advice from your CF team, our online content and information resources can help you make informed decisions about your lifestyle, treatment and care, however you're affected by cystic fibrosis.

All of our information is written and reviewed by experienced information and health professionals.

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



How to order

Visit <u>cysticfibrosis.org.uk/information</u> to download all of our information and support resources. Information can change frequently, so this is the best place to find the most up-to-date information. This also helps us save money on printing and postage costs.

If you'd prefer printed copies, you can:

- Visit <u>cysticfibrosis.org.uk/information</u> and order our information packs by using our order forms
- Contact our Helpline on 0300 373 1000 or by emailing helpline@cysticfibrosis.org.uk

Watch our videos on YouTube

Our YouTube channel is full of videos on various aspects of CF, including what the condition is, what it's like to live with CF, information about our research and more. Visit youtube.com/cftrust



Support when you need it

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

Our Helpline

Any questions? We're here to help. Our confidential Helpline offers a listening ear, and information and support on all aspects of CF, whether you need guidance on a specific problem or are just looking for a friendly, knowledgeable person to chat to. Call us on 0300 373 1000 or email helpline@cysticfibrosis.org.uk

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 <u>cysticfibrosis.org.uk/benefits</u> 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 on helpline@cysticfibrosis.org.uk or 0300 373 1000 to access this service.

Grants

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

These include:

- emergency grants
- transplant grants to assist with the associated costs of assessment for transplant
- funeral grants
- health and wellbeing grants to help fund exercise equipment or household goods
- grants to support education, prescription costs and holidays

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



Opportunities for young people

Youth Advisory Group

Our Youth Advisory Group (YAG) is a way for young people aged 14–25 to influence the work of the Trust and ensure the voices of young people with CF are heard. They discuss, share, laugh and cough their way through monthly online hangouts. It's a great way to meet amazing people and make a difference. Email cfyouth@cysticfibrosis.org.uk to find out how you or a young person you know could take part.

Digital Youth Programme

We offer an engaging programme of online activities, designed to empower, inform, inspire and bring young people with CF together. Everything is digital so young people with CF can connect with each other virtually!

Find out more at cysticfibrosis.org.uk/CFyouth



Let's connect

We understand that CF can be an isolating condition – the risk of cross-infection means those with CF can't meet up, and parents of children with CF can't connect with each other as easily as they might like. Here are a few ways that you can connect with other people in the CF community:

- Chat with another parent through our CF Connect service, which matches you with a trained parent volunteer who you can talk to in confidence about having a child with cystic fibrosis. To be put in touch with another parent through CF Connect contact our Helpline on 0300 373 1000 or email helpline@cysticfibrosis.org.uk
- Read about other people's experiences of living with CF on our website or in our magazine, CF Life, at cysticfibrosis.org.uk/magazine
- Chat to other people affected by CF on our online forum at cysticfibrosis.org.uk/forum
- Follow us on our social media channels and share your experiences with other members of the CF community.
- Cystic Fibrosis Trust





@cftrust

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!

We update this catalogue annually. For updates and changes to our information resources, please check our website regularly at cysticfibrosis.org.uk/ information



About cystic fibrosis

Cystic fibrosis is a genetic condition affecting more than 10,600 people in the UK. Our 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? leaflet, 2019.
Order code: CFLEAFLET

Support for all factsheet, 2016.
Order code: CFSUPPORTLFLT

CF Connect leaflet, 2015.
Order code: CFCONNECTLFLT

How does CF affect the body? Find out using the interactive body at cysticfibrosis.org.uk/body

- Cystic fibrosis and cross-infection
 cysticfibrosis.org.uk/crossinfection
- Symptoms of cystic fibrosis cysticfibrosis.org.uk/symptoms
- What is a genotype? video cysticfibrosis.org.uk/genetics





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.

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



Watch our film for new parents or read Sarah's diary, which she kept in the weeks after her son, Rhys, was diagnosed with CF: cysticfibrosis.org.uk/newdiagnosis



- Late diagnosis factsheet, 2020.
 Order code: CFADULTHOOD
- The sweat test factsheet, 2016.
 Order code: CFSWEAT

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 booklet, 2019.

Order code: CFBODYIMAGE





 Festival planning guide for young people, 2017.

BOD

FIBROSIS

WEIGHT POSTURAL CHANGES

Visit <u>cysticfibrosis.org.uk/festivals</u> to download the guide and view our festival tips for parents.

Mindfulness exercises
 cysticfibrosis.org.uk/mindfulness



 Achieving a healthy weight in cystic fibrosis leaflet, 2018.

Order code: CFNUWEIGHT

 Calcium and bone health in cystic fibrosis leaflet, 2019.

Order code: CFNUVITS

Please note: If you order this resource in print, it will also include **iron in the cystic fibrosis diet** and **vitamin supplements in cystic fibrosis** in one leaflet.

 Drinking alcohol and cystic fibrosis leaflet, 2018.
 Order code: CFNUALCOHOL



Eating well for children with cystic fibrosis leaflet, 2019. Order code: **CFNUPAED1**

Please note: If you order this resource in print, it will also include pancreatic insufficiency and nutrition in cystic fibrosis (babies) and weaning information for babies with cystic fibrosis in one leaflet.

- Enzyme refusal in children with cystic fibrosis leaflet, 2020. Order code: CFNUENZREF
- Exercise nutrition in cystic fibrosis leaflet, 2018.
 Order code: CFNUEXERCISE
- Food refusal in children with cystic fibrosis leaflet, 2019. Order code: CFNUFOODREF
- Gastrointestinal issues in cystic fibrosis leaflet, 2020. Order code: CFNUGIISSUES
- Healthy eating and cystic fibrosis leaflet, 2019.
 Order code: CFNUHEALTHY
- Iron in the cystic fibrosis diet leaflet, 2019.
 Order code: CENUVITS

Please note: If you order this resource in print, it will also include calcium and bone health in cystic fibrosis and vitamin supplements in cystic fibrosis in one leaflet.

 Learning to swallow enzymes for children with cystic fibrosis leaflet, 2020.
 Order code: CFNUSWALLOW

Leaving home and eating well with cystic fibrosis leaflet, 2018. Order code: CFNULEAVE





- Nutrition and pregnancy in cystic fibrosis leaflet, 2018. Order code: CFNUPREG
- Pancreatic enzyme supplements and cystic fibrosis leaflet, 2020. Order code: CFNUENZYME
- Pancreatic sufficiency and nutrition in cystic fibrosis (babies) leaflet, 2019. Available to download only from cysticfibrosis.org.uk/nutritionleaflets
- Pancreatic insufficiency and nutrition in cystic fibrosis (babies) leaflet, 2019.

Order code: CFNUPAED1

Please note: If you order this resource in print, it will also include eating well for children with cystic fibrosis and weaning information for babies with cystic fibrosis in one leaflet.

 Post-lung transplant nutrition for people with cystic fibrosis leaflet. 2019.

Order code: CFNUPOSTLUNG

Salt in the cystic fibrosis diet leaflet, 2019.
Order code: CFNUHYDSALT

Please note: If you order this resource in print, it will also include staying hydrated and cystic fibrosis in one leaflet.

Staying hydrated and cystic fibrosis leaflet, 2019.
Order code: CFNUHYDSALT

Please note: If you order this resource in print, it will also include salt in the cystic fibrosis diet in one leaflet.

Vitamin supplements in cystic fibrosis leaflet, 2019.
 Order code: CFNUVITS

Please note: If you order this resource in print, it will also include calcium and bone health in cystic fibrosis and iron in the cystic fibrosis diet in one leaflet.

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

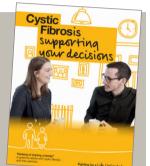
Please note: If you order this resource in print, it will also include eating well for children with cystic fibrosis and pancreatic insufficiency and nutrition in cystic fibrosis (babies) in one leaflet.

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





 Family genetic testing: The family cascade screening programme for cystic fibrosis factsheet. 2015.

Order code: CFCASCADE

Watch our video, **Starting a family if you have cystic fibrosis**, featuring two families and a CF doctor answering some questions on fertility and cystic fibrosis: youtube.com/watch?v=59MUG9fG87I



Treatments, therapies and care

Thanks to breakthroughs in medication, physiotherapy and other treatments, people with CF are living longer and healthier lives than ever before. We have information on all the latest and best treatments for managing the symptoms of CF, from trusted medications to exercises you can do at home. Please speak to your CF team before making any changes to your treatment regime.

- Emotional and social impacts of Kaftrio factsheet, 2020. PDF only, available to download from cysticfibrosis.org.uk/factsheets
- Home intravenous therapy factsheet, 2016.
 Order code: CFHOME
- Inhaled therapy for people with cystic fibrosis factsheet, 2016.
 Order code: CFINHALED
- Steroid treatment in cystic fibrosis factsheet, 2015.
 Order code: CFSTEROID
- The use of ports in cystic fibrosis factsheet, 2015.
 Order code: CFPORTACATH

Physiotherapy

- Active cycles of breathing technique leaflet, 2018.
 Order code: CFACBT
- Airway clearance for babies and young children with cystic fibrosis leaflet. Coming soon!
- Airway clearance plan leaflet, 2018.
 Order code: CFACP
- Autogenic drainage (AD) leaflet, 2018.
 Order code: CFAUTO
- Bubble PEP leaflet, 2018.
 Order code: CFBUBBLE
- How to improve your posture leaflet, 2018.
 Order code: CFPOSTURE
- How to use your PEP Mask leaflet, 2018.
 Order code: CFPEP
- PARI PEP™ leaflet, 2018.
 Order code: CFPARI
- Pelvic floor exercises (female) leaflet, 2018.
 Order code: CFPELVIC
- Pelvic floor exercises in CF. A leaflet for children and young people. Coming soon!

- Physiotherapy treatment in cystic fibrosis: Airway clearance techniques factsheet, 2013.
 PDF only, available to download from cysticfibrosis.org.uk/factsheets
- Stress incontinence in children with CF. A leaflet for parents and carers. Coming soon!
- The Acapella® choice leaflet, 2018.

 Order code: CFACAPELLA
- Urinary incontinence factsheet, 2013.
 PDF only, available to download from cysticfibrosis.org.uk/factsheets

Transplants

- Cystic fibrosis and transplant booklet, 2018.
 Order code: CFTRANSBOOK
- 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

Taking part in clinical trials

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

Clinical trials for young people

The Junior Agents comic is for primary-age children with CF to introduce them to the concept of clinical trials. It can be used alongside the information sheet for parents, while the resource for young people is for older children.

- Junior Agents comic, 2020. Order code: CFCYPCOMIC
- Clinical trials resource for parents of young children, 2020. Order code: CFCYPRESPAR
- Clinical trials resource for young people, 2020.
 Order code: CFCYPRESYP

Watch our video on clinical trials for young people, Could you change the future of cystic fibrosis? by visiting cysticfibrosis.org.uk/youngpeopletrials





Moving from paediatric to adult care (transition)

Your transition to adult care: A guide for young people pack, 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

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



Money and benefits

Cystic fibrosis can bring its own financial burden. 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 <u>cysticfibrosis.org.uk/financialsupport</u> for detailed information about all of the financial support we offer.

- Disability Living Allowance (DLA) for children under
 16 Visit cysticfibrosis.org.uk/DLA
- Completing the DLA form: Hints and tips factsheet, 2019. PDF only, available to download from cysticfibrosis.org.uk/DLA
- Personal Independence Payment (PIP) for those aged 16+ Visit <u>cysticfibrosis.org.uk/PIP</u>
- A guide to the assessment criteria for PIP Visit <u>cysticfibrosis.org.uk/PIPcriteria</u>
- Guidance for PIP: Face-to-face assessments
 factsheet, 2018. PDF only, available to download
 from cysticfibrosis.org.uk/PIP
- Prescription charges for cystic fibrosis Visit cysticfibrosis.org.uk/prescriptions

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



Education and work

Pre-school and primary school

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



Patient information awards Highly commended

Primary school pack: For school staff, 2016. Three A4 information sheets and an individual healthcare plan booklet in a presentation folder. Order code: CFPSCHFOLDER (also available to download from cysticfibrosis.org.uk/school)

Secondary 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, 2016. Two A4 information sheets in a presentation folder. Order code: CFSSCHFOLDER

- My CF Planner an individual healthcare plan, 2020.
 PDF only, available to download from cysticfibrosis.org.uk/secondaryschool
- 3 class passes to share with your teacher if you need to move seat, or leave class to cough or go to the toilet.
 Visit <u>cysticfibrosis.org.uk/secondaryschool</u> to order or download
- My friend has CF cysticfibrosis.org.uk/friend

Leaving school

Schools out...what's next?! booklet for young people, 2018.
Order code: CFPOST16YP

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

Information for training providers, colleges and universities, 2018. PDF only, available to download from cysticfibrosis.org.uk/leavingschool

Watch our video, **The A–Z of cystic fibrosis** by visiting <u>youtube</u>.
com/watch?v=AVg24S_pSmo



Resources for children

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

- Seb's Best Game hardback children's book, 2018.
 Order code: CFKIDSBOOK2
- The Lost Collar Investigation hardback children's book, 2018.

Order code: CFKIDSBOOK1





Watch our video **Getting Nosey** about **CF with Oli and Nush** at <u>youtube.com/watch?v=Wul-</u>72eMrlQl&feature=emb_logo



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.

- Cystic fibrosis and bone health factsheet, 2020.
 Order code: CFBONE
- Cystic fibrosis-related diabetes factsheet, 2017.
 Order code: CFDIABETES
- Cystic fibrosis-related liver disease factsheet, 2017.
 Order code: CFLIVER
- Melioidosis and worldwide travel factsheet, 2017.
 Order code: CFMEL

Additional symptoms of cystic fibrosis

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

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



- Advanced care planning guidance for clinicians, 2017. PDF only, available to download from cysticfibrosis.org.uk/planningahead

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

- 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

Information resources 2021/22

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 clinicians and other health professionals involved in treating people with the condition. 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.

- Antibiotic treatment for cystic fibrosis, 2009
- European cystic fibrosis bone mineralisation guidelines, 2011
- Laboratory standards for processing microbiological samples from people with cystic fibrosis, 2010
- Management of cystic fibrosis-related diabetes mellitus, 2004
- Methicillin-resistant Staphylococcus Aureus (MRSA), 2008
- National consensus standards for the nursing management of cystic fibrosis, 2001

- NTM guidelines, 2017 (amended March 2018)
- Nutritional management of cystic fibrosis, 2016
- Pharmacy standards of care, 2011
- 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
- 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

Please note our consensus documents are available to download online at cysticfibrosis.org.uk/consensus

Cystic Fibrosis our focus

How can you help us?

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

- Spare some time to organise a fundraising event.
- Make a donation either personally or get your workplace involved.
- Lend your voice to our campaigns and raise awareness of the condition.

Take a look at <u>cysticfibrosis.org.uk/getinvolved</u> for more information on getting involved with the Trust. To make a donation please visit <u>cysticfibrosis.org.uk/donate</u>.

Visit our website <u>cysticfibrosis.org.uk</u> to find out more about cystic fibrosis.







The Cystic Fibrosis Trust is the only UK-wide charity making a daily difference to the lives of people with cystic fibrosis, and those who care for them.

Helpline: 0300 373 1000 helpline@cysticfibrosis.org.uk

Give us your feedback on our information by emailing infoteam@cysticfibrosis.org.uk