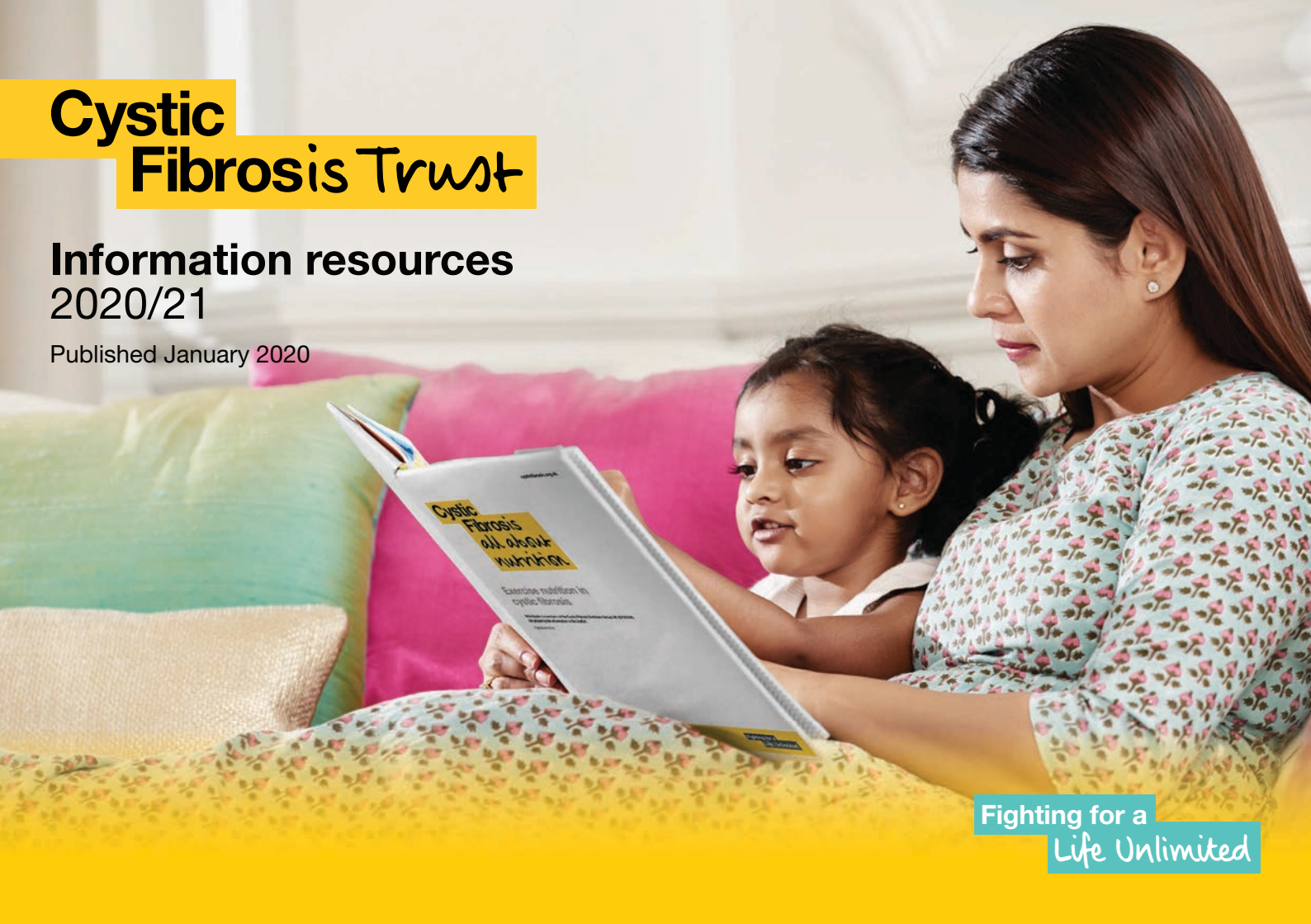


# Cystic Fibrosis Trust

## Information resources 2020/21

Published January 2020



Fighting for a  
Life Unlimited

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## 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](https://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](https://cysticfibrosis.org.uk/donate)



## How to order

Visit [cysticfibrosis.org.uk/information](https://cysticfibrosis.org.uk/information) 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 [cysticfibrosis.org.uk/information](https://cysticfibrosis.org.uk/information) and order our information packs by using our order forms
- Contact our Helpline on 0300 373 1000 or by emailing [helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk)

## Other formats

If you would like to access our information in a different format to meet your needs, please contact [infoteam@cysticfibrosis.org.uk](mailto:infoteam@cysticfibrosis.org.uk) to discuss how we can help.

## 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](https://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](mailto: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 [cysticfibrosis.org.uk/benefits](https://cysticfibrosis.org.uk/benefits) or by contacting our Helpline.

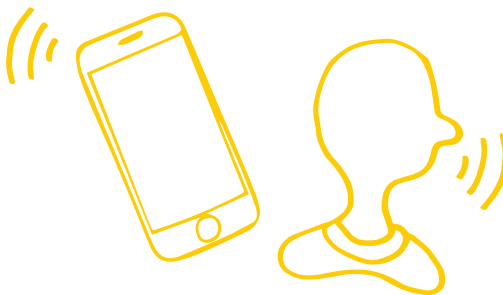
## Grants

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](https://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](mailto: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](https://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](mailto: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](https://cysticfibrosis.org.uk/magazine)
- Chat to other people affected by CF on our online forum at [cysticfibrosis.org.uk/forum](https://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](https://www.facebook.com/CysticFibrosisTrust)  [@cftrustuk](https://www.instagram.com/cftrustuk)  [@cftrust](https://twitter.com/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](mailto: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](https://cysticfibrosis.org.uk/information)



## About cystic fibrosis

Cystic fibrosis is a genetic condition affecting more than 10,500 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](https://cysticfibrosis.org.uk/body) 

- **Cystic fibrosis and cross-infection**   
[cysticfibrosis.org.uk/crossinfection](https://cysticfibrosis.org.uk/crossinfection)

- **Symptoms of cystic fibrosis**   
[cysticfibrosis.org.uk/symptoms](https://cysticfibrosis.org.uk/symptoms)

- **What is a genotype?** video   
[cysticfibrosis.org.uk/genetics](https://cysticfibrosis.org.uk/genetics)

 **Web content**  **Video**

## 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](https://cysticfibrosis.org.uk/newdiagnosis) to explore some extra resources.

- **Parent information pack, 2015, including the friends and family guide** leaflets.

Order code: **CFPARENTPACK**



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](https://cysticfibrosis.org.uk/newdiagnosis)



- **Diagnosis in adulthood** factsheet, 2016.
- 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**



- **Growing older with cystic fibrosis** [cysticfibrosis.org.uk/growingolder](https://cysticfibrosis.org.uk/growingolder) 



- **Festival planning guide for young people**, 2017. 

Visit [cysticfibrosis.org.uk/festivals](https://cysticfibrosis.org.uk/festivals) to download the guide and view our festival tips for parents.

- **Mindfulness exercises** [cysticfibrosis.org.uk/mindfulness](https://cysticfibrosis.org.uk/mindfulness) 

## Exercise and nutrition

- **Achieving a healthy weight in cystic fibrosis** leaflet, 2018.

Order code: **CFNUWEIGHT**

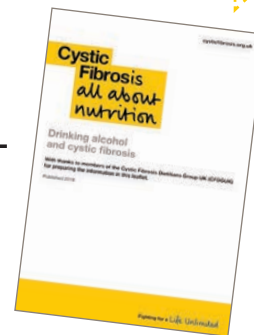
- **Calcium and bone health in cystic fibrosis** leaflet, 2019.

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\*
- **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\*
- **Healthy eating and cystic fibrosis** leaflet, 2019.  
Order code: **CFNUHEALTHY**
- **Iron in the cystic fibrosis diet** leaflet, 2019\*

**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\*

- **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\*
- **Pancreatic sufficiency and nutrition in cystic fibrosis (babies)** leaflet, 2019. Available to download only from [cysticfibrosis.org.uk/nutritionleaflets](https://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.

\*Available soon

- **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**

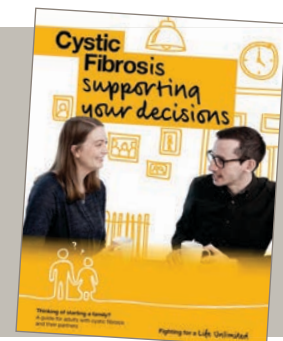
**Please note:** If you order this resource in print, it will also include **eating well for children with cystic fibrosis** and **pancreatic insufficiency and nutrition in cystic fibrosis (babies)** in one leaflet.

## 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](https://www.youtube.com/watch?v=59MUG9fG87I)



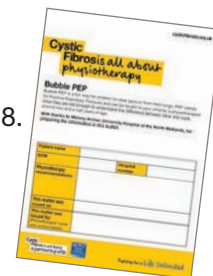
## Treatments, therapies and care

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.

- **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: **CFSTERIOD**
- **The use of ports in cystic fibrosis** factsheet, 2015.  
Order code: **CFPORTACATH**

## Physiotherapy

- **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**
- **Physiotherapy treatment for babies and toddlers with cystic fibrosis** factsheet, 2013.  
PDF only, available to download from [cysticfibrosis.org.uk/factsheets](https://cysticfibrosis.org.uk/factsheets)
- **Physiotherapy treatment in cystic fibrosis: Airway clearance techniques** factsheet, 2013.  
PDF only, available to download from [cysticfibrosis.org.uk/factsheets](https://cysticfibrosis.org.uk/factsheets)

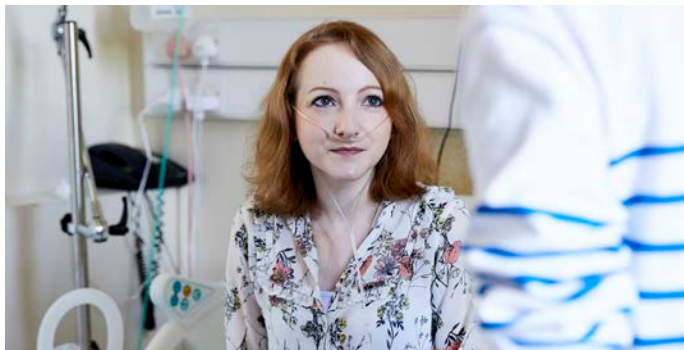


- **The Acapella® choice** leaflet, 2018.  
Order code: **CFACAPELLA**

- **Urinary incontinence** factsheet, 2013.  
PDF only, available to download from  
[cysticfibrosis.org.uk/factsheets](https://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: **CFTRANSBKPF**



## 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**

Watch our video on clinical trials for young people,  
**Could you change the future of cystic fibrosis?**  
by visiting [cysticfibrosis.org.uk/youngpeopletrials](https://cysticfibrosis.org.uk/youngpeopletrials)



## Moving from paediatric to adult care

- **Transition from paediatric to adult care: A guide for young people** factsheet, 2013.
- **Transition from paediatric to adult care: A guide for parents** factsheet, 2013.
- **Transition from paediatric to adult care: A guide for commissioners, hospital and clinical teams** factsheet, 2013.

All available to download only from  
[cysticfibrosis.org.uk/factsheets](https://cysticfibrosis.org.uk/factsheets)

## 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.

You can also visit [cysticfibrosis.org.uk/financialsupport](https://cysticfibrosis.org.uk/financialsupport)

- **Financial help** factsheet, 2013. PDF only, available to download from [cysticfibrosis.org.uk/factsheets](https://cysticfibrosis.org.uk/factsheets)
- **Disability Living Allowance (DLA) for children under 16** Visit [cysticfibrosis.org.uk/DLA](https://cysticfibrosis.org.uk/DLA) 🌐
- **Completing the DLA form: Hints and tips** factsheet, 2019. PDF only, available to download from [cysticfibrosis.org.uk/DLA](https://cysticfibrosis.org.uk/DLA)
- **Personal Independence Payment (PIP) for those aged 16+** Visit [cysticfibrosis.org.uk/PIP](https://cysticfibrosis.org.uk/PIP) 🌐
- **A guide to the assessment criteria for PIP** Visit [cysticfibrosis.org.uk/PIPcriteria](https://cysticfibrosis.org.uk/PIPcriteria) 🌐
- **Guidance for PIP: Face-to-face assessments** factsheet, 2018. PDF only, available to download from [cysticfibrosis.org.uk/PIP](https://cysticfibrosis.org.uk/PIP)

- **Prescription charges for cystic fibrosis**  
Visit [cysticfibrosis.org.uk/prescriptions](https://cysticfibrosis.org.uk/prescriptions) 🌐

- **Prescription charges** factsheet, 2019. PDF only, available to download from [cysticfibrosis.org.uk/prescriptions](https://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](mailto:helpline@cysticfibrosis.org.uk)



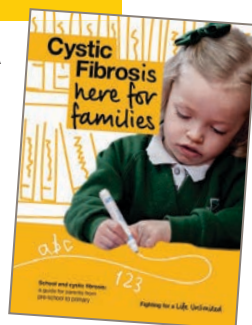
Sangeeta Enright, Welfare and Rights Advisor

## Education and work

- **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](http://cysticfibrosis.org.uk/school))

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

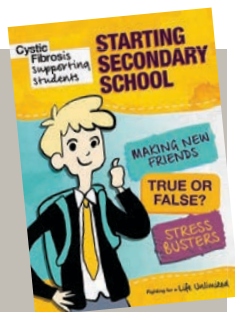
- **Starting secondary school magazine for young people**, 2017.  
Order code: **CFSSCHMAG**



Patient information awards  
Highly commended



Patient information awards  
Runner-up



- **Secondary school pack: For school staff**, 2016.  
Two A4 information sheets in a presentation folder.  
Order code: **CFSSCHFOLDER**

- **My friend has CF**  
[cysticfibrosis.org.uk/friend](http://cysticfibrosis.org.uk/friend)

- **Individual healthcare plan: For young people**  
Coming soon!

- **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/leavingsschool](http://cysticfibrosis.org.uk/leavingsschool)



Watch our video, **The A-Z of cystic fibrosis** by visiting [youtube.com/watch?v=AVg24S\\_pSmo](https://youtube.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](http://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 nosy about CF with Oli and Nush** at [youtube.com/watch?v=Wul-72eMriQI&feature=emb\\_logo](https://youtube.com/watch?v=Wul-72eMriQI&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, 2015.  
Order code: **CF BONE**
- **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](http://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](https://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](https://cysticfibrosis.org.uk/planningahead)

- **End of life care course for clinicians, 2017.** Available

online at [cfcourse-online.co.uk/eolm-landing](https://cfcourse-online.co.uk/eolm-landing) 

## 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](mailto: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**

## 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**, 2017
- **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](https://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 [cysticfibrosis.org.uk/getinvolved](https://cysticfibrosis.org.uk/getinvolved) for more information on getting involved with the Trust. To make a donation please visit [cysticfibrosis.org.uk/donate](https://cysticfibrosis.org.uk/donate).

Visit our website [cysticfibrosis.org.uk](https://cysticfibrosis.org.uk) to find out more about cystic fibrosis.



# Cystic Fibrosis Trust

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](mailto:helpline@cysticfibrosis.org.uk)

Give us your feedback on our information by emailing [infoteam@cysticfibrosis.org.uk](mailto:infoteam@cysticfibrosis.org.uk)