

# 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 cvsticfibrosis.org.uk/donate.



Patient Information Forum

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

postage costs.



Download our information resources from our website cysticfibrosis.org.uk/information

- Call 0300 373 1000 or 020 3795 2184, Monday-Friday 10am-4pm
- Email helpline@cysticfibrosis.org.uk

love to hear from you!

# 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



Watch our videos voutube.com/cftrust

Order printed copies by contacting our Helpline

• 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

# Contents

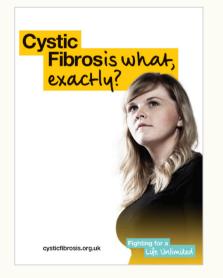
Our information	2
How to get our information	3
Topics	
About cystic fibrosis	6
After a diagnosis	8
Living well with cystic fibrosis	10
Exercise and nutrition	11
Family planning	14
Treatments, therapies and care	16
Physiotherapy and lung health	18
Transplants	20
Taking part in clinical trials	21
Transitioning from paediatric to	22
adult CF care	
Money and benefits	24
Education and work	26
Resources for children	28
CF related conditions	30
End of life planning	32
Bereavement	33
Support for people in the community	34
Resources for professionals	36
How can you get involved?	38

4 Information resources 2023/24



# 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

No-one understands what you're going through like people who've

CF Connect is a peer support service from You can access our CF Connect service

Cystic Fibrosis Trust, for parents, carers by contacting our Helpline. Give us a call

and families of children and young people or send us an email and one of the team

been through it too.

CF Connect volunteers offer a listening

ear and the chance to share experiences

way. Those who have used the service

have found it really helpful to speak to

someone who understands what it's like

to be a parent or someone who cares for a

in an understanding and supportive

cysticfibrosis.org.uk

with CF.

child with CF.

liust needed

to talk to someone

who understood

what I was feeling

because they'd

been there..."

will put you in touch with one of our

trained parent volunteers. Whether you're

a parent, grandparent, uncle, aunt, or even

Uniting for a life unlimited

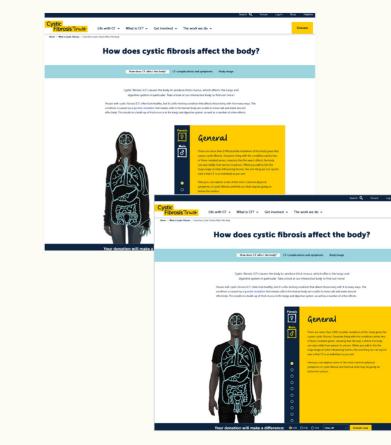
a friend of the family, our volunteers are

there to listen and help.

Helpline 0300 373 1000

helpline@cysticfibrosis.org.uk

FibrosisTrw



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.





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



Late diagnosis, 2020. Order code: CFADULTHOOD



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



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

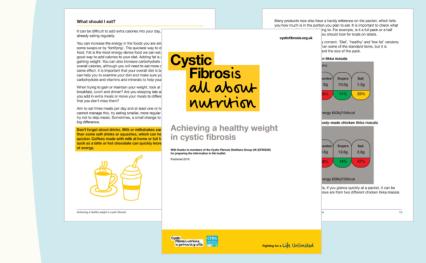


**Body image and cystic fibrosis**, 2019. Order code: CFBODYIMAGE

# 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



#### Do I need to take enzymes with everything Leat?

Enzymes should be taken with all foods containing fat protein or carbohydrate. This includes all meals, mik-based drinks and most snack The only foods that do not need enzymes are: All types of fruit and fruit juices. Most vegetables and all vegetable juices. Jelly and sorbet Fruit gums/jellies, pastilles, boiled sweets and mints Squash and fizzy drinks Alcohol (although creamy drinks such as Irish cream liqueur or milk-based cocktails do need enzymes).

#### How do I know if I am taking enough enzymes?

The amount of ennumes that you will pead is you individual. You pead to take enough for your body to fully digest and absorb your food. Weight gain is usually a good indicator of how well the enzymes are working.

Not taking enough enzymes will result in undigested food passing through your body. This can cause symptoms of abdominal pain, bloating, excess wind and loose stools that are paie, oily or difficult to flush away. You may lose weight or find it difficult to gain weight.

If you have any of these symptoms, discuss this with your dietitian or doctor



#### What if I forget to take my enzymes?

Occasionally forgetting to take enzymes will cause nothing more drastic than possibly an upset stomach. If you forget to take them over a longer period of time, you will experience weight loss and nutrient deficiencies. This can affect your body's ability to fight off chest infections. You are also more at risk of developing distal intestinal obstruction syndrome (DIOS) complication of CF that causes a blockage in the bowel. We have a leaflet called 'Gastrointestinal issues in cystic fibrosis' which gives more information about DIOS. See cysticfibrosis.org.uk/nutritionleaflets.

If enzymes are frequeten at the start of a meal, they can still be taken during If enzymes are torgotten at the start of a meal, they can still be taken during the meal or at the end of the meal. Some people find it helpful to keep a supply of enzymes at places they often go, such as at work, or in in their bag or jacket pocket. This way they always have a supply readily available.

#### Is there anything else I need to know?

cysticfibrosis.org.uk/nutritionleaflets.

Enzyme capsules should be stored in an airtight container in a cool place. as exposure to heat and air can reduce their effectiveness Check use by dates. You should rotate your stock of enzymes, using older stock first before starting new ones. It is important to drink plenty of fluid to keep your digestive system working well. A rough guide for adults and children with cystic fibrosis over 14 years of age is to try and have 2,000–3,000 ml/day. See the leaflet on Staving Hydrated for more information about fluid intake at



#### 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



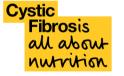
#### These factsheets come as one pack



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



cysticfibrosis.org.uk

Pancreatic enzyme supplement and cystic fibrosis

The Cystic Fibrosis Trust is grateful to the dietitians from the Cystic Fibrosis Dietitian Group UK (CEDGUK) who prepared the information in this leaflet. Published 2020



and cystic fibrosis, 2020.

Order code: CFNUENZYME

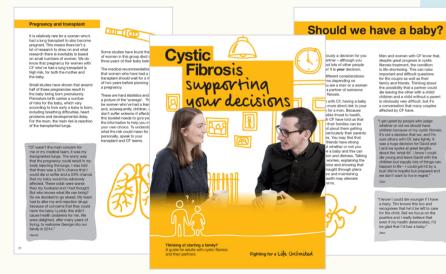
### Other information available

- Enzyme refusal in children with cystic fibrosis, 2020. Order code: CFNUEN7RFF
- Food refusal in children with cvstic fibrosis, 2019. Order code: CFNUFOODREF
- Learning to swallow enzymes for children with cystic fibrosis, 2020. Order code: CENUSWALLOW
- 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 lives than ever before. Please speak to your CF team before making any changes to your treatment regime.



Lans and tables Kathris				
I am not taking Kaftrio There are many reasons why someone with CF may not be taking Katrio. Some of these are explored below. You might be feeling some resemment on hearing about the benefits of Katrio from others with CF. Some have said they	Cystic Fibrosis Trws+			phights many of the complex and ople with CF in the UK who have been on, we are learning more about how it
experience guilt for having these feelings, just as those who are taking Kaftrio may feel guilty that some in their community are currently feeling left behind.	FibrosisTrust			rience some, all or none of the feelings ere is no right or wrong way to feel. otions
You might find it useful to share your feelings with someone. Your CF team will know that you aren't taking Kaftrio and will want to support you in any way they can.	Kaftrio – comple			e waited for something that treats the er than just the symptoms, for a long t close to you started taking Kaftrio. grafitude, impatience for the expected
I cannot benefit from Kaftrio due to the CF gene variants I have Someone's genotype – the CF gene variants (mutations) they have – is one reason that they might not be able to benefit from Kaftrio.	individual experi	iences		ture. Alongside these welcome feelings, erienced other feelings. These may be ome of them may be unexpected and
Kaftrio is only approved for people with CF who have specific CF gene variants, because it does not work for other variants. You can read more about Kaftrio and gene variants on the <b>Cystic Fibrosis</b> <b>Trust webdie</b>	March 2022			g time, or are interfering with your life rts, do speak with your CF team. They
Those who are still waiting for treatment for their gene variants				u may have experienced include:
may be experiencing a miniture of emotions, including fluctuation, sadness, anger and worry. It may also be difficult to explain to well- meaning filends and family who have heard about Katrio in the news or on social media, that you or someone close to you are not in fact able to benefit from it. There are also some rare variants that we do not know much about, including whether a person with these variants could benefit from				th CF – After starting Kaftrio, how CF may have changed. Some people at CF may not have such a big place in le you might have wished for this, some twhat you have been used to can also people with CF have grown up with it restions about the future or feelings
Kaftrio. Over time more people with CF may be able to benefit from Kaftrio as clinical trials continue to show health improvements for additional groups.				unsettling and you might need to give pe a common emotion when someone
As many people are aware, major treatment breakthroughs are still needed for some people with CF. Research into new treatments for those who cannot benefit from Katrio is already happening. You can find more information about this <b>here</b> .				inity that others do not have, even if sonally. This can be difficult to explain re – If your health has improved a
My child is too young to take Kaffrio In the UK, people with CF under the age of 6 with CF gene variants that would benefit from Kafrio are currently unable to take it, uniest they are involved in a trit ic under compassionale usa. This may change in the future as more trials are being done in younger are groups taking Kafrio.				going to have less of an impact on we hopes about the future. This can be quite scary or unsettling, especially if knocked by health issues or other life to adjust to a changed view of the may not realise that the possibility of I very complicated.
yey group and gr				Having more hope for the future may ink about your pace. You may think made and how things might have been bite to take Kafthio earlier. You may find the about periods of illeness in the past, a hard or traumatic your experience of sese emotions is very important.
Kathio – complex and individual experiences			and the second	siences
		Uniting for	a life unlimited	

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



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

**ululul**ulul

# Other information available

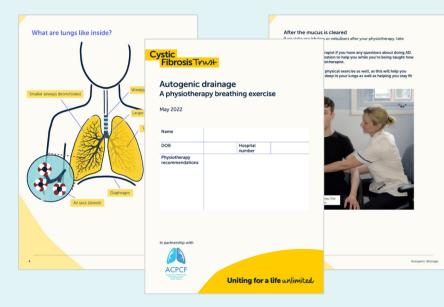
• Steroid treatment in cystic fibrosis, 2015. Order code: CFSTEROID

## 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.

\*\*\*\*\*\*\*\*\*\*\*\*\*\* \*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\* 

......

\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*

-----

Victorial Contractorial Contractoria Contractorial Contract

\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\* ......

ALL DESCRIPTION OF THE PARTY OF

VIII IIIIIIIIIIIIII 

...... ......

ALL DESCRIPTION OF THE PARTY OF

ALL LALLE

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



Use these

together!





Before any see medicine or them the top through a number of the yea, long with Of holes. The tot will find cat: If the medicine presented with the second transfer watch watch watch whether its table from an official schedule its table from an official table of the medicine of the second an an angent results. Non could be servor gravit bettering.



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

20 Information resources 2023/24

# Update coming soon!



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



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



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

# 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** 

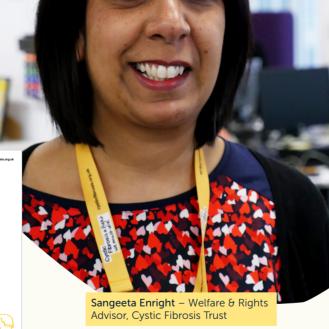




Completing the DLA form: Hints and tips, 2019. cysticfibrosis.org.uk/DLA

In and suggest the second sec







Uniting for a life unlimited

# 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





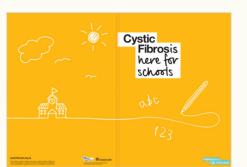
# **Education and work**



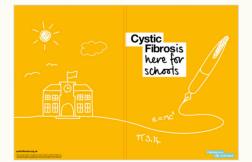
School and cystic fibrosis: A guide for parents from pre-school to primary, 2016. Order code: CFPSCHBOOK



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



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



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



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



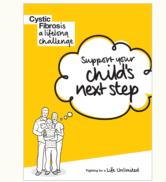
My CF Planner an individual healthcare plan, 2020. cysticfibrosis.org.uk/secondaryschool

### Update coming soon!

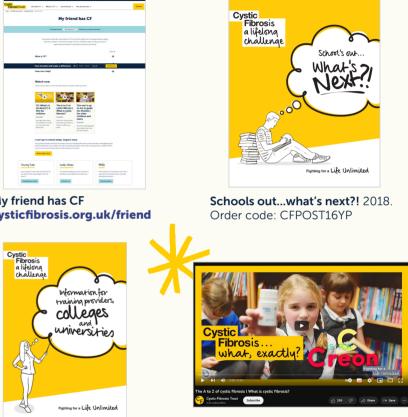
I have a medical condition which means I urgently need to use the toilet.

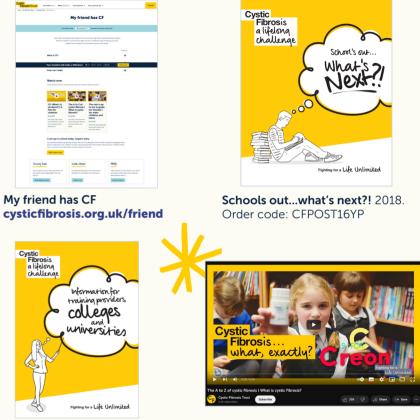
Please allow me to leave discreetly. Cystic Fibrosis Trust

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



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





colleges and universities, 2018.

Information for training providers, cysticfibrosis.org.uk/leavingschool The A–Z of cystic fibrosis

# **Resources for children**

Seb's Best Game





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

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

В 0  $\sim$ Layla, 7 Noah, 8 Jack, 3 Jason, 10

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



Zaara, 11



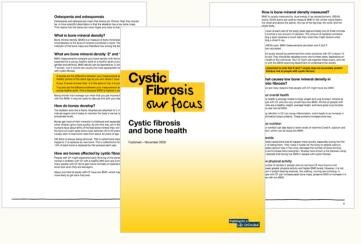
Huffin

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



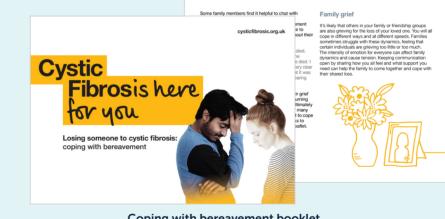
#### End of life planning booklet, 2017. Order code: CFEOLBOOK

# **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: CEBEREBOOK



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



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

#### cvsticfibrosis.org.uk 33

systicfibrosis ora uk

# 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.

#### 34 Information resources 2023/24

### **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

		J. 34	impung processi	··9
<section-header><section-header><section-header><section-header><section-header><text></text></section-header></section-header></section-header></section-header></section-header>		Cystic Fibrosis Trwat- Laboratory Standards for Processing Microbiological Samples from People with Cystic Fibrosis Second edition December 2022	<text><text><section-header><text><text></text></text></section-header></text></text>	<section-header><section-header><list-item><list-item><list-item><section-header><section-header><section-header><section-header></section-header></section-header></section-header></section-header></list-item></list-item></list-item></section-header></section-header>
The overall prevalence of lower respiratory tract infection with MRSA among people with CF has Laboratory Standards for Processing Microbiological Sam	with an intensive course of antibiotics aimed at eradicating the organism from the airways. glies from People with Cystic Fibrosis. 16		ds for Processing Microbiological Samp	ies from People with Cystic Fibrosis 25

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

2.1 Why screen for CF diabetes?	2.3 Difficulties in diagnosing CF diabetes
CF diadeets III was an	Contract of the contract of th
any treatment of CID has been shown to reduce but not abolish the relative increased moniality risk for individuals with CID compared to those without. <sup>11</sup>	tolerance and potentially increase the prevalence of type 2 diabetes as the proportion of people with CT who are converged increases. • Where 120-minute glucose levels are normal or
wenoz." A few small studies of insulin treatment show benefit for individuals with IG2 and abnormalities of glucose handling which do not meet the otheria	<ul> <li>Where 120-minute glucose levels are normal or impaired after QCTT, glucose levels can be over 11 invectiv. If glucose is measured at 30, 60 or 90 minutes during the test.</li> </ul>
	to COT surveys, 13 hosp ground game     tool and a constraint game of game
Cystic Fibrosis Tru Manag	ement of fibrosis diabetes
Cystic Fibrosis Tra Manag cystic fi Second editi	ement of fibrosis diabetes

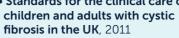
fibrosis diabetes, 2022

#### 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



### 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



Standards for the clinical care of



# 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 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.



© Cystic Fibrosis Trust 2023. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: 2nd Floor, One Aldgate, London EC3N 1RE.

Uniting for a life unlimited