Cystic Fibrosis Trust

CF Life

Issue 21
cysticfibrosis.org.uk

Your stories
Dating and CF

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Starting school with confidence

Ask the expert
Answering questions on diet and CF

Uniting for a life unlimited

Welcome!

Back in the spring, everyone at the Trust was very excited to see Nicole share her experience of CF on the Channel 4 show *First Dates*. It was a brilliant platform to raise vital awareness, and we're delighted that Nicole is also sharing her story in this issue of CF Life (**page 14**), including her top tips for dating with CF.

It's important for us to share the many different experiences and realities of living with CF. For some people, like Nicole, modulator treatments have had a really positive impact, but we know that is not true for everyone. On **page 26**, we hear from Abi, who recently won one of our Helen Barrett Bright Idea Awards for her princess party business, **Fairytales and Tiaras**. As well as what winning the award means to her, Abi shared how it feels to not be able to benefit from modulator treatments, and how it can sometimes be like an "illness inside an illness".

Elsewhere in this edition, we explore phage therapy (**page 8**) – what it is, how it could be used as a potential treatment for CF lung infections, and the research we're funding to find out more. We also speak to CF dietitian Darren Sills (**page 12**), who answers questions from the community on everything from gut symptoms to healthy eating.

We hope you find this issue insightful, and please get in touch with your ideas and feedback. We always love to hear from all of our wonderful supporters.

The CF Life team

Social

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Cystic Fibrosis Trust

forum.cysticfibrosis.org.uk

cftrust

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Useful contacts

Donations
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Events and fundraising enquiries
020 3795 2176
events@cysticfibrosis.org.uk

Cystic Fibrosis Trust Helpline
0300 373 1000
helpline@cysticfibrosis.org.uk

Our confidential Helpline offers general advice, support and information on any aspect of cystic fibrosis, including help with financial support.

All magazine correspondence should be sent to:

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Uniting for a life *unlimited*

What's inside

Issue 21 – September 2026

On the cover: Nicole, who features on p14
This page: Top; Darren, who features on p12
Bottom; Abi, who features on p26

We're always looking for new people to feature in CF Life. If you'd like to share your experiences, please get in touch with us at **magazine@cysticfibrosis.org.uk**

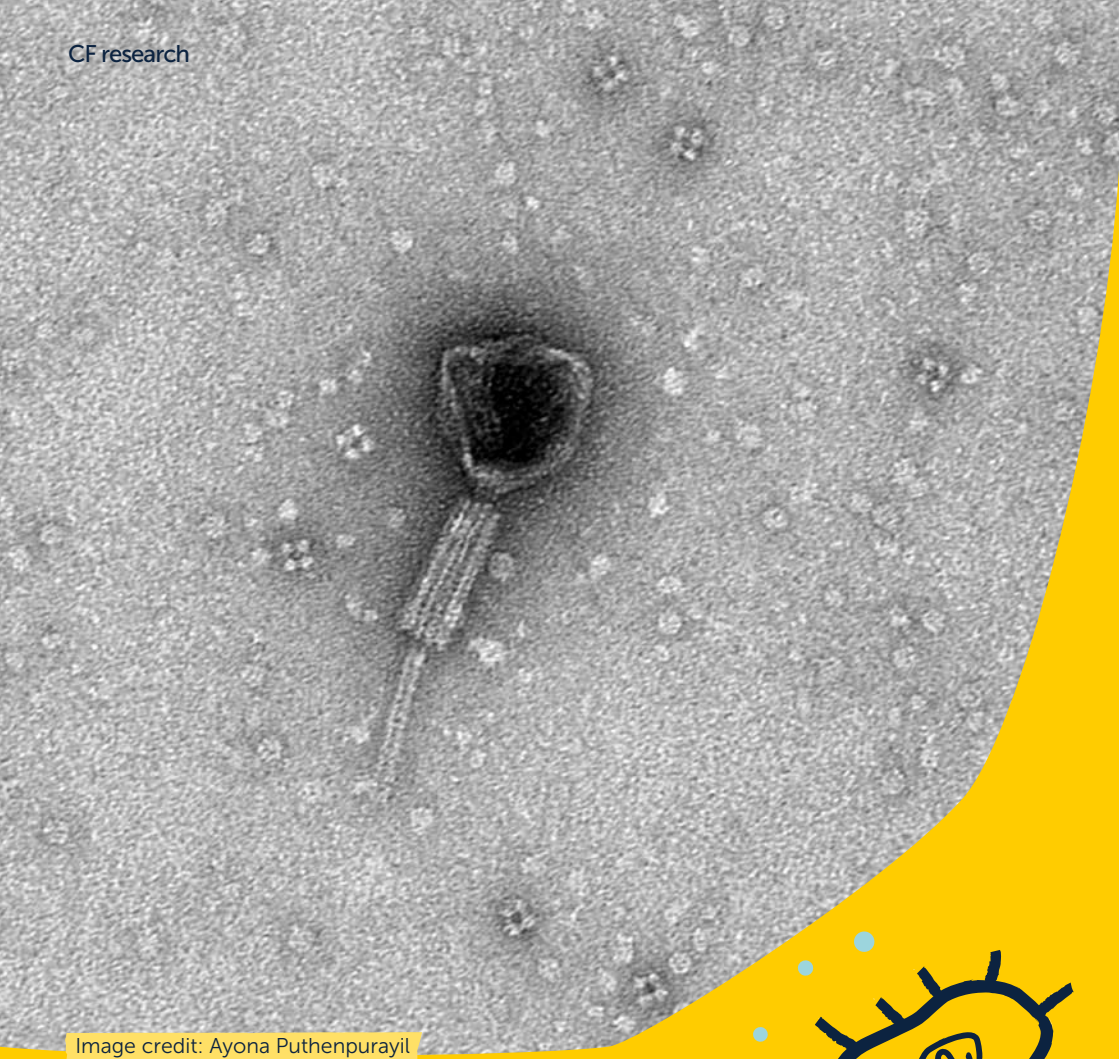
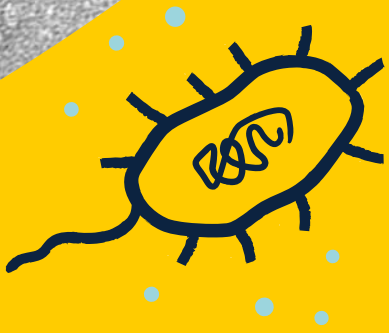


Image credit: Ayona Puthenpurayil

Research for the (ph)ages



Over the last few years, there has been renewed interest in developing bacteriophage treatments for infections. They are being explored as a treatment for cystic fibrosis (CF) lung infections in a range of different ways. In this article, we explore what phages are, the different ways that they could be used as a treatment, and how the Trust is supporting their development.

> **"Even after Kaftrio, I've still struggled with *Pseudomonas aeruginosa* infections. I have a lot of antibiotic resistance to it and that's why phages and phage therapy are really exciting and interesting."**
>
> Candice, who has CF

Candice

What are bacteriophages?

Also known as 'phages', bacteriophages are naturally occurring, bacteria-killing viruses. They kill bacteria by infecting them. They are very specific about which bacteria they infect, sometimes only infecting a specific variant of an infection-causing bacteria.

Why is there interest in phage therapy?

Phage therapy could become another option for treating CF lung infections. In addition, as they are so specific, researchers hope that using phages as a therapy can reduce the side effects seen with antibiotics – both in terms of not attacking 'good bacteria' in the lungs and elsewhere, and also having less toxicity in other parts of the body.

How could phage therapy be useful in CF?

Researchers hope phage therapy can be used as a treatment for long-term CF lung infections, particularly where antibiotic options have become very limited. Ideally, in the future, phage therapy may also be considered as a treatment to clear early infections from the lungs. This is known medically as 'eradication therapy'.

Why is more research into phage therapy needed?

Scientists need to find the phages that are available in nature and test and sometimes adapt them in the lab for effectiveness and safety. Next, more detailed and extensive tests are carried out to develop them into a treatment. This includes making phage effective and safe to deliver into the lungs of people with CF, working out how much phage to give and when, and finding ways to make enough 'medical-grade' phage to use in these treatments.

"Even after Kaftrio, which was very life-changing for me, I've still struggled with *Pseudomonas aeruginosa* infections. I have a lot of antibiotic resistance to it and that's why phages and phage therapy are really exciting and interesting. If phage therapy became widely available it would mean just more options. I know that maybe doesn't sound like such an impactful thing, but it really is," says Candice, who has CF.

Finding phage to treat *Burkholderia cepacia* complex infections

Finding the right phages for the right bacteria can be extremely difficult. One reason why it is so tricky is that there are so many to choose from. For every grain of sand in the world, there are a trillion phages! Trust-funded researchers in Cardiff University and University of Leicester will be combining their strengths to look for phages that could be used in treatments for the *Burkholderia cepacia* complex group of bacteria.

Infections caused by *Burkholderia cepacia* complex (BCC) bacteria are very difficult infections to treat. Researchers in Cardiff, including PhD student Dan Shelley, are searching for dormant *Burkholderia* phages as a starting point for a phage therapy. Any phages they find will be genetically engineered in the lab to make them safer and more effective as a potential treatment.

Dr Jessica Lewis at the University of Leicester hopes to isolate phages from the environment, test their effectiveness against *Burkholderia* in the lab, and then create 'production strains' of bacteria ready to be used to generate large amounts of phage for when phage treatments are required.

You can read more about her research on our website at cysticfibrosis.org.uk/Lewis-DA

Making access to phage therapy clearer and easier

One of the aims of our Trailfinder-CF Innovation Hub is to develop new and more tailored treatment approaches for CF lung infections, by developing phage therapy. It's led by Professor Jo Fothergill, from the University of Liverpool.

Professor Jo Fothergill

"At the moment, phage therapy is only used as a last resort. We want to change that, particularly for people with chronic lung infections, making access easier and clearer for doctors and people with CF," explained Professor Fothergill.

"As part of the research underway, we hope to increase the number of phages available to treat a range of different bacterial infections that people with CF develop. We will also test new mixtures of phages, improve ways to get them into the lungs, and set up UK-based production. We will also develop simple lab tests to help doctors see if a phage will work for a particular person."

The Trailfinder-CF Innovation Hub is part of the Translational Innovation Hub Network for CF Lung Health and Infection funded by the Trust and LifeArc.

Learn more about the Trailfinder-CF Innovation Hub at **cysticfibrosis.org.uk/trailfinder-CF**

Guidelines to accelerate development of phage therapy

There are a number of steps researchers need to complete after finding out in the lab that a potential medicine could work before it can become available as a medicine. This includes providing regulators with clear results that the medicine works as expected in the lab and is safe when given to people, through to the best way of giving the medicines and how often they should be given.

When a completely new type of medicine, such as a phage therapy, is being developed, these steps can be even harder, as there are no previous examples of what experiments to do and what results to expect. This is where Target Product Profiles, or TPPs, can be helpful. TPPs are a wishlist of desirable properties for new medicines that can provide guidance for researchers developing the medicines.

Michelle, who has CF

Researchers within the Trailfinder-CF Innovation Hub have joined forces with colleagues in the CF AMR Syndicate to deliver a set of TPPs to guide the development of phage therapies to treat lung infections in CF. These TPPs have been informed by the experiences and insights of people living with CF.

"Having the needs of people with CF, clinicians, and researchers gathered and presented in a single framework is the best building block we could have. I really enjoyed having a small input into the development of the TPPs, seeing the different avenues explored to gather that insight. The TPPs should be shared with every organisation, developer, researcher, and clinician involved in the process of developing new phage treatments," Michelle, who has CF and was a member of the steering committee for the development of the phage TPP.

"Children with CF growing up today will still be at risk of infections. I hope that they may never have to face resistance to antibiotics or the expectation that they just have to suffer through toxic treatments. Phages have the potential to offer them a way to manage infections quickly and maintain their life as a well person with CF."

If you have other questions about phage therapy and the research we're funding into it, visit **cysticfibrosis.org.uk/phage**

In focus

STORMing ahead

The CF STORM study investigated whether people with CF taking Kaftrio could safely reduce their treatment burden. We spoke to the chief investigators, Professor Kevin Southern and Dr Gwyneth Davies, about the aims of the study, how people with CF were involved in designing and running it, and what they found.

What was the study about?

STORM stands for **S**treamlining **T**reatments **O**r **R**educing **M**edications, which summarises what the study aimed to achieve.

People with CF who are stable on the modulator treatment Kaftrio wanted to know whether they could safely stop some of the most burdensome daily nebulised treatments they commonly take.

In particular, we looked at stopping Dornase alfa (also known as DNase) and hypertonic saline. These are known as mucoactive treatments. They are normally taken one to three times a day and are time-consuming therapies.

We designed the study to find out whether stopping these treatments would result in a significant drop in lung function over 12 months.

How were people with CF involved in designing the study and how it was run?

The CF community's priorities for research got us thinking about whether we could safely stop any existing treatments. People with CF helped us decide what treatments the study would stop, how they wanted their health monitored, and how to make the study easy for people to take part in.

We wanted the study to fit in with routine care. If you are doing a study looking at how to reduce and simplify treatment burden, you don't want the study itself to add extra burden!

Dr Gwyneth Davies

> "If you are doing a study looking at whether you can reduce and simplify treatment burden, you don't want the study itself to add extra burden!"

The study found that, on average, stopping nebulised mucoactive therapies did not negatively impact lung function compared with continuing them. This was true for children and adults, and across different levels of lung disease severities included in the study. People with a lung function of FEV_1 percent predicted of 40% and above were included in the study.

What do the results mean for me?

The results from this research study offer reassurance for people with CF who have considered stopping their mucoactive nebulisers. Decisions about stopping therapies should be made in partnership with your CF team and monitored carefully to ensure that this has not been detrimental in your individual case.

Professor Kevin Southern

Find out more about the CF STORM study on our website **cysticfibrosis.org.uk/cfstorm**

CF STORM
CLEARING THE AIR

We are all #TeamCF

We are so grateful for the passion of our #TeamCF fundraisers and we want to celebrate just some of the team's incredible efforts.

The Watchet Harbour community bookshop (Photo: Peter W Mather Photography)

Watchet Harbour community bookshop

Seventeen years ago, Melanie and her late husband, Alan, founded a community bookshop to fundraise in memory of their beloved son, Tom. Alongside five founding members and 60 dedicated volunteers, they have raised an incredible £200,000 for Cystic Fibrosis Trust.

Reflecting on their journey, Melanie shared: **"The bookshop softened our grief after Tom died. It was a way to keep his memory alive for as long as possible."**

Now, as the shop closes its doors one final time, we want to thank the local community, especially Mary and Jeff, who have been running the shop and keeping this vital momentum going. Their collective achievement stands as a lasting tribute to Tom's memory.

Audrey

After being diagnosed at 26 and spending time to get to know and understand her diagnosis, Audrey decided to run for the Trust.

"I really wanted to share the news of my diagnosis through a running event, and that is when I knew I wanted to run for Cystic Fibrosis Trust," said Audrey.

Audrey completed the half marathon at this year's Edinburgh Marathon Festival in an excellent 2 hours and 19 minutes, raising £871.

Audrey

Jodie

Inspired by the resilience shown by her 17-year-old sister Brooke, who has CF, one fundraiser braved a skydive to support the Trust and raised over £500.

Jodie's advice to fundraisers is **"Just go for it! Every penny raised makes a tangible difference in the lives of people like my sister, and knowing you are helping to fund life-changing research is the most rewarding feeling."**

Jodie and Brooke

Now it's your turn!

Visit **cysticfibrosis.org.uk/teamcf** and see what's coming up. Whether you host a festive fundraiser, sign up for a challenge event, or nominate us to be a charity partner, every penny raised makes a difference. Not sure where to start? Message our team at **events@cysticfibrosis.org.uk** and we'll help you get started.

Events for 2026/27

4 October – Cardiff Half Marathon
11 October – Royal Parks Half Marathon, London
15 December – Carols by Candlelight, London
4 April – London Landmarks Half Marathon
4 April – Brighton Marathon
24–25 April – London Marathon
2 May – Belfast Marathon
29–30 May – Edinburgh Marathon Festival
Various – London to Paris Cycle/Skydive

Ask the expert

CF dietitian and researcher Darren Sills answers some of our questions about diet and CF – from how to eat a healthy, balanced diet to what his research is telling us about gut symptoms and nutrition.

How can a CF dietitian support people with CF?

The expertise of a CF dietitian is all about blending nutritional evidence with real life. We look at the big picture – combining clinical, social, and health factors into practical, everyday advice around food.

Because CF looks different at every stage of life, our support changes too. For children and young people, we work with families to make sure nutritional advice fits into regular family life.

As people transition from the teenage years to adult life, we give practical advice on managing their diet independently. In adulthood, we support people navigating specific life stages and health changes, such as pregnancy, adjusting pancreatic enzyme needs, or a new diagnosis like CF diabetes.

Ultimately, our goal is to empower people with the knowledge and skills to make nutritional choices that fit their unique lives.

What does a healthy, balanced diet look like for a person with CF?

The latest guidelines recommend that people with CF who maintain a stable, healthy weight should aim for a balanced diet similar to the general population. However, there is a catch: the average modern diet isn't always very healthy!

A truly healthy, balanced diet for someone with CF should include:

- **Wholegrain carbohydrates:** Base your meals around fibre-rich options like wholemeal pasta, brown rice, wholegrain bread, and oats.
- **Plenty of plants:** Aim for at least five portions of fruit and vegetables every day to get a wide range of essential vitamins and antioxidants.
- **Diverse proteins:** Try to include more plant-based proteins such as beans, lentils, tofu, and meat-free alternatives. Limit red meat and processed meats to once or twice a week at most.
- **Healthy fats:** Include fish regularly. Oily fish like salmon, sardines, and mackerel are fantastic for heart and joint health.
- **Balance, not restriction:** Food is to be celebrated and enjoyed! It is absolutely right to include treats, but the key is mindfulness and trying not to rely on high-sugar foods too frequently.

What could the GRAMPUS-CF study tell us about the role diet plays in managing gut symptoms?

Early results suggest that the relationship between gut symptoms and diet is fascinatingly complex!

Looking at patterns in gut symptoms, people with the most severe symptoms appear to eat differently, though the statistical difference isn't quite significant. What isn't clear is whether the food causes the symptoms, or whether the symptoms force people to change what they feel able to eat. However, when we look at dietary habits, some really interesting and clear patterns emerge:

- **Skipping meals and reflux:** Those who regularly skipped meals were more prone to experiencing reflux.
- **Sugar and abdominal pain:** There was a possible link between a higher-sugar diet with increased abdominal pain.
- **The 'good diet' benefit:** Most encouragingly, people who ate the highest-quality diet reported the lowest overall symptom burden.

While we need to see if these exact patterns hold true as we look at our later data, the takeaway message is clear: eating a healthy, varied diet seems to support a happier gut. We still have plenty of work to do. Next, we will be diving deeper into how dietary habits link up with the bacteria in the colon (the microbiome) and tracking how these gut symptoms change over time. Stay tuned!

Find our resources on diet and nutrition at **cysticfibrosis.org.uk/nutrition**

"I really wanted CF to be part of the show"

Earlier this year, Nicole, 27, a yoga teacher and business owner who has CF, appeared on Channel 4's *First Dates*, where she met her boyfriend, Matthew. We caught up with her to find out more about the experience, her top tips for dating with cystic fibrosis, and why she wanted to raise awareness of CF on the show.

> "I think the younger me would have loved to see someone with CF on telly speaking about it openly and honestly."

I actually applied for First Dates as a joke. It was back in June 2023. I found myself single and a friend of mine said I should apply to go on some shows. I said the only show I'd ever do would be *First Dates* because it's just one episode. You have a nice meal and then you're done. Over a year later, I got the call!

I tried to keep the whole thing fun and not take it too seriously. But when they walked me over to the restaurant, that was the moment it really hit me. They were like, "Ok, Nicole, are you ready? Cameras rolling, 3, 2, 1, off you go" – and suddenly I was walking down what felt like the longest corridor I'd ever experienced.

From the moment Matthew and I met, the conversation just flowed. We had so much to talk about. We talked about travel, our jobs, family, music – it was just constant conversation. There wasn't a single awkward moment.

I made sure to talk about CF when applying. After Kaftrio, my health improved so much that I suddenly had this whole new outlook on life. I wanted more travel, more freedom, and to grow my business. So when it came to dating, I really wanted someone whose vision for the future aligned with this new chapter of my life.

I also really wanted CF to be part of the show. I wanted to show that people's understanding of CF may be outdated and that the future is much brighter now.

I think the younger me would have loved to see someone with CF on telly speaking about it openly and honestly. It would have made me feel less alone and more understood. I hope for parents of children who have been newly diagnosed that it offers a sense of reassurance.

I had a few different plans of how to bring CF up on the date. At first, I thought I'd mention it when I took my Creon before eating. I said, "I hope you don't mind, I'm just going to take some tablets before we eat." But he was so polite that he just said, "Oh yes, that's absolutely fine," and didn't ask any questions. So that option disappeared. Eventually, I linked it to my business and said: "One of the reasons my business is called Breathe With Ease is because I have a life-limiting condition that affects my lungs. I have cystic fibrosis."

> **"I made sure to talk about CF when applying. After Kaftrio, my health improved so much that I suddenly had this whole new outlook on life."**

I have a sentence I always use to explain CF: **"I'm not sure if you've heard of it or know much about it, but I was born with cystic fibrosis. I take daily medication to help maintain my health. It doesn't just affect my lungs – it also affects my pancreas and digestive system."** Once I'd said that, I could see him understand and feel more comfortable asking questions.

Matthew and I are still together and it's all been really exciting. We've got lots of lovely things planned for the future!

Nicole's tips for dating with CF

1. Don't feel forced to bring up CF until you're ready
Nicole says: "I wanted to talk about CF on *First Dates*, because I wanted to use the opportunity to raise awareness of the condition. But usually, I wait until the right time to talk about CF, because it's a very personal topic for me."

2. When you feel ready to talk about it, plan how to introduce it
Nicole says: "It can be hard to describe CF because it's such a complex condition, so I plan in advance how I'm going to bring it up in a way that feels comfortable for me."

3. When planning the date, do what makes you feel comfortable
Nicole says: "I recommend making a little list of things you feel comfortable doing, and don't be afraid to suggest activities that suit you and your health."

4. Encourage your date to ask questions, rather than turn to Google
Nicole says: "Once you've broken the ice about your CF, try and make sure your date feels open to asking you questions about it, rather than going away and googling it."

“Every mile was for my dad”

Elise was one of 24 dedicated runners who took part in the London Marathon in memory of a loved one. She ran in honour of her dad, Marc, who sadly died when Elise was just 12 years old.

Growing up, Elise saw first-hand the daily realities of living with cystic fibrosis. These experiences not only inspired her to take on the London Marathon but also shaped her future. Elise is now studying Biomedical Science at Cardiff University and working on several projects focused on understanding and treating CF.

After completing the marathon, Elise created a tribute page in memory of Marc. This page provides a lasting space for family and friends to remember him, while ensuring Elise’s incredible fundraising efforts continue to create a meaningful legacy in her dad’s name.

If you would like to find out more about creating a tribute or memory page for your loved one, please contact our In Memory Officer, Susan, at **susan.jackson@cysticfibrosis.org.uk**.

What's on your mind?

Our Helpline Manager, Matthew, answers some of your questions about life with cystic fibrosis.

My son had CF and died six months ago. He was in his thirties. I was ok at first. We had said our goodbyes. He was very unwell. Now, I'm left struggling. No one understands. Can you help?

Matthew's answer:
Firstly, I want to say I'm so sorry to hear about your son. Whether or not we see death coming, it doesn't make grief any easier to navigate, and I'm glad you have reached out for support.

You can have a look at our information resources at **cysticfibrosis.org.uk/publications**. This includes our resource **Losing someone to cystic fibrosis: coping with bereavement**. We also have a specific resource, **Bereavement: losing a child of any age to cystic fibrosis**, which I hope you'll find helpful.

We have partnered with **Marie Curie** so that those who are grieving the loss of someone with CF can access their telephone support service.

People have told us lots of times that it can be hard to access bereavement support because many people don't understand or aren't aware of CF. We have trained their staff and volunteer team about CF, what it means to lose someone to the condition. They have also heard first-hand from people who have lost someone to CF.

You can get **six free telephone sessions** with the same **bereavement support volunteer**. It's a safe, confidential space to talk about your feelings around bereavement. Each session can last up to 45 minutes. It is not a counselling service. **It is open to anyone over the age of 18 who has lost someone to CF who is an adult.**

To access the service, you can fill in the form to book a call on Marie Curie's website at **mariecurie.org.uk** and search **'Telephone bereavement support'**. Make sure that you put on your form that you are grieving someone who had CF, so they can match you with a volunteer who has had our training. Once you have filled in the online form, you will be contacted by the team at Marie Curie.

If you'd prefer to access support digitally, you can also access GriefChat from our bereavement webpage at **cysticfibrosis.org.uk/bereavement**. GriefChat offers compassionate, confidential emotional support from experienced bereavement counsellors through a live chat service.

For more information on accessing these services, or to talk anything through, please contact our friendly Helpline team. **You can call us on 0300 373 1000**, email us at **helpline@cysticfibrosis.org.uk**, or message us on WhatsApp on **07361 582053**.

For anyone who loses a child under 18 to CF, **our Helpline** can provide information on services that can provide support.

Take 5

We asked you, the CF community, for your top tips for travelling with cystic fibrosis. Here's what you told us...

Rachel
Chat with your CF team about pre-holiday elective IVs if needed, as well as flight letters and assessments and back-up meds. You could also ask your team for spare nebuliser mouthpieces and physio devices, as this will make washing up much easier.

Book holidays appropriate to the pace you can manage. We used to book lots of busy trips, but this time we're opting for a restful holiday as it allows me to get the rest I need each day to feel well.

Laura
Always take extra medication! I take extra Creon and pack my own salted crisps. I also always have a letter from my CF team regarding medication supply that I have with me and I also take a pack of antibiotics in case a chest infection flares up.

Lucy
My top tip if flying is to always ring the airline first so they can help. Sometimes I get complimentary seats or extra baggage allowance. I also book with a travel agent who understands me and my health needs.

Megan
If your meds need keeping cool, get a cool pouch for them. And if staying somewhere without air conditioning, ask at reception if you can put your meds in their fridge. Plan in advance so you have time to get enough meds and allow extra time for the pharmacy in case they have run out of something.

Regan
Research the nearest hospitals, so if you need medical attention, you know exactly where to go and you don't need to try and figure it out if you're unwell.

For more information and tips on travelling with CF, including our travel insurance guide, visit **cysticfibrosis.org.uk/travel**

Kate, aged 11, who has CF

In focus

Starting school with confidence

For many families, starting nursery or school is exciting, but it can also bring up lots of questions when your child has CF. Parents often tell us they're thinking about everything from Creon and infection control to school trips, absences, and whether staff will understand their child's needs.

That's why we've updated our nursery and primary school guide. It brings together practical advice from clinicians and the experiences of parents who have already navigated nursery and primary school with their children, helping you feel informed and prepared for every step of the journey. Our aim is to give you the knowledge and confidence to help ensure your child's education isn't limited by CF.

"Our nursery sends us the menus in advance so we can calculate the Creon dosage. When they are unsure they phone to confirm, but they have also become more confident to make the calculations themselves. This is based on experience and conversations we've had with them so we're happy for them to have this freedom."

Julia, mum to Olivia, aged 4

Julia and Olivia

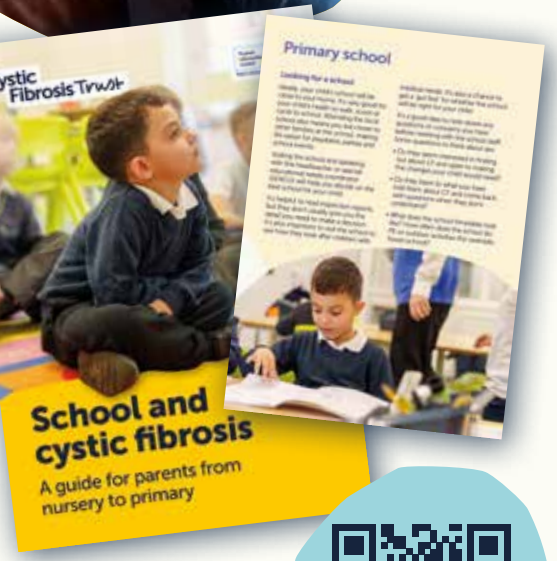
What's in the guide?

The guide includes practical information on:

- choosing a nursery or primary school
- talking to staff about your child's needs
- infection control, including outdoor play and cross-infection
- giving Creon at school or nursery
- school trips
- how your CF team can support you and your child's school
- answering questions from other children about CF
- what to do if problems arise
- real-life tips from parents who have already navigated nursery and primary school with their children.

"When Kate started school, I let parents know via the WhatsApp group that Kate had CF. I said that if they or their children had any questions, they should ask me or Kate directly. Kate was always very open, and actually as the children grew up together some of the kids would spot potential risks ahead of the teachers."

Catherine, mum to Kate, aged 11



Scan the QR code to view our new schools resources

We'd love to know what you think

Has the guide been useful? Is there anything we've missed?

Email **infoteam@cysticfibrosis.org.uk** and let us know what you think. Your feedback will help us continue improving this resource for families.

The guide is now available at **cysticfibrosis.org.uk/school**

Prefer a printed copy? You can order one free of charge by calling our Helpline on **0300 373 1000**.

"Anyone can make a difference. Even just speaking about CF could be overheard by someone who is going through a new diagnosis."

Uniting for a life without limits

When Megan first shared the news of her two-year-old son Ruadhán's cystic fibrosis (CF) diagnosis, she didn't just find a listening ear – she found an amazing community ready to support the whole family and their fundraising efforts.

Ruadhán's start in life was far from easy. Born with meconium ileus (MI), his early days were marked by a stressful stay in the Neonatal Intensive Care Unit (NICU) and a subsequent hospital admission due to failure to thrive.

"We had so many scares in the hospital, and everything was so overwhelming," Megan told us. **"At that point, I didn't know what future Ruadhán was going to have – if any. Everything was so tough."**

During those dark moments, a nurse told Megan that she would eventually look back at this period differently. She was right. Today, Ruadhán is a headstrong, resilient little boy.

Megan's experience inspired her to speak out and raise awareness: **"Whenever I post about CF or do fundraising, I think back to how scared and unsure we all were at the start. If I had known someone who posted or fundraised for CF back then, it would have shown me that people can live with CF and they are ok!"**

Fundraising as a family

Inspired to start fundraising for Cystic Fibrosis Trust, Megan spotted the Belfast Marathon Relay and proposed a family challenge. Fundraising as a team has transformed their experience. **"It's great to fundraise as part of a team because there are more people to spread awareness,"** Megan explains.

"It's also amazing to motivate each other and keep each other going throughout the run. It has made us a lot closer as a family. We are always asking each other what the next challenge is that we can take on!"

Friends and others in the CF community also got involved by sharing fundraising pages, talking to others about cystic fibrosis, and helping the family reach their fundraising targets.

For Megan and her family, fundraising is about more than just raising money; it is about bringing people together to provide hope that "one day, there will be a cure for CF".

Everyone can make a difference

To anyone thinking about fundraising for the Trust, Megan's message is: **"Anyone can make a difference. Even just speaking about CF could be overheard by someone who is going through a new diagnosis. That's why I make sure to be open about it. Even small donations make a difference in providing support for families, and just spreading the word is incredibly important."**

Megan hopes that as Ruadhán grows up, he too will be open and proud in sharing his story, showing the world that cystic fibrosis doesn't define him.

#TeamCF

Are you ready to unite for #TeamCF?

Gather your friends, family, or colleagues and sign up to #TeamCF today!

Whether you host a festive fundraiser, sign up for a challenge event, or nominate us to be a charity partner, every penny raised makes a huge difference. Not sure where to start? Check out some of our upcoming events at **cysticfibrosis.org.uk/TeamCF**, or get in touch with our team directly at **events@cysticfibrosis.org.uk**

10 Years of YAG

This year marks the 10th anniversary of our Youth Advisory Group (YAG). To celebrate this milestone, we spoke to Nicola, who has been involved since the first meeting in 2016 and is now a co-facilitator, and Lizzie, who joined in August 2025.

Could you share some of your standout moments from your time with YAG?

Lizzie: A major highlight has been working on our current phlebotomy project, which is looking at needle phobia in children with CF. It's something I'm passionate about as I have personal experience of needle phobia. I've been involved in designing questionnaires for healthcare professionals to understand their perspectives, which has been really cool as I've never done anything like that before.

Nicola: One highlight was working on the Kaftrio survey, which we launched shortly after the modulator became available. It was a critical opportunity to ensure young people's voices and diverse experiences were represented. Another massive standout was the **Cracking the CF Code** dictionary project. Coming back later as a co-facilitator and seeing that initial idea grow into a beautifully illustrated, printed resource was incredibly rewarding.

CF can be an isolating condition due to cross-infection. What was your experience of connecting with others with cystic fibrosis before YAG?

Lizzie: I had never knowingly met or spoken to anyone with CF before joining YAG. Finding YAG made me feel less alone in my CF. It's great to talk to people who have had completely different journeys. For instance, I wasn't diagnosed until I was eight, whereas others have been in and out of hospital since birth. But, despite those differences, we share so much in common.

Lizzie

Nicola

Nicola, what's it been like going from being part of YAG to being a co-facilitator of the group?

Nicola: It's been really rewarding. Being a member of YAG gave me so much confidence when I was a teen and so many opportunities to engage with various aspects of the Trust, so it's been really nice to be on the other side of that now and continue to support the group.

Lizzie, you mentioned that sometimes, when you're living with a chronic condition, it's important to just acknowledge when things are tough. How does YAG help with that?

Lizzie: Yes, sometimes CF is just rubbish, and it's okay to have a bad day. In the wider world, people often tell you to "have a positive mindset" or "go for a walk". At YAG, if you've had a bad day, people don't try to force solutions on you; they just say, "I'm sorry, I hope tomorrow is better." Even if you don't feel like talking, you can just sit quietly and listen.

The CF landscape has changed dramatically over the last decade. What are your hopes for the next 10 years?

Nicola: Modulators have been life-changing, but they don't work for everyone. Some people aren't eligible, and others, like myself, can't take them due to severe side effects. My hope for the next 10 years is that we don't forget this different side of the story. We need a concerted effort to research and develop alternative treatment options so that every single person with CF has a viable option moving forward.

Lizzie: We also need much more research into the additional conditions and comorbidities that develop as the CF population ages, such as cardiovascular disease.

What has being part of YAG given you?

Nicola: Something I've really valued is just the space to talk about both CF-related issues and non-CF-related issues with people who just kind of get it and without it being in a parent-led or clinical setting.

Lizzie: It's reminded me that there's a lot more to me than my CF. For every single member of YAG, having CF is probably the least interesting thing about them. The fact that they've got CF is kind of our common denominator, but then our friendships are built on so much more.

Find out more about our Youth Advisory Group (YAG) at **cysticfibrosis.org.uk/YAG**

Pass the MIC

"When I am dressed as a princess, I feel like I don't have CF at all"

Becoming a princess

Abi is the founder of princess party business Fairytales and Tiaras and a recent winner of our Helen Barrett Bright Idea Awards, which provides financial support for people with CF who want to turn their business dreams into a reality. We caught up with Abi to find out more about why she started the business, the reality of juggling work and CF, and what it's like not being able to benefit from modulators.

Growing up with CF

I was diagnosed with CF at five months old. Growing up, I was always quite well and had a high lung function, but I had stomach issues. When I was around 11 or 12, I had my first bronchoscopy and began having to have IV antibiotics once a year. This then went up to twice a year and then three times a year up to the age of 16, when I moved into adult care.

I got a portacath and now have IVs every three months, but I'm allergic to a lot of antibiotics. I also can't go on modulators because of my genetics. That's the biggest struggle out of anything. I don't have many options, and I am constantly getting *Pseudomonas aeruginosa*, *Staphylococcus aureus* and *Aspergillus*.

I used to have a strong online community of people with CF, but since modulators have come along, I've felt pushed out. I don't have a community with people with CF my age, who can't take modulators, which is sad. It's like an illness inside of an illness.

A bright idea

I decided I wanted to start my own business because I wanted to be my own boss. I get such terrible anxiety asking for time off. I don't like to stand out because my CF feels like a problem. I want to prove it's not an issue, but it is, it's a part of me.

I auditioned for a princess party company and it sparked a real passion in me. When I was dressed as a princess, I felt like I didn't have CF at all. The place I worked closed their business because the owner had a baby. I wanted to stay loyal to her, but when she said she was leaving, I knew it was the right time. I had no money, so I had to start from scratch.

My mum told me to look for grants with the Trust. When I saw the Helen Barrett Bright Idea award, I realised it would be perfect. When I got the call, I found out I'd received the full amount that I asked for, and I was in shock. It's going to seriously change my world.

I was having such a rough time, so it was perfect timing. I recently made my first purchase with the funding and can't wait to get started. To anyone thinking of applying, I'd say just go for it! You've got absolutely nothing to lose and so much to gain. It gave me the confidence to believe not only in my business, but in myself.

What I love most about what I do is the pure innocence, wonder, and curiosity children have. They don't see my CF or everything I've been through; they just see the princess they've always dreamed of meeting.

As a child, I often felt vulnerable, different, and like I had to grow up too quickly because of cystic fibrosis. So being able to give another child a day where they can simply be a child means everything to me.

My advice to anyone with CF thinking of starting a business is: don't wait until you feel healthy enough or ready enough, because with CF that day may never come. Start where you are, work at your own pace and be kind to yourself on the difficult days. There will be times when CF has to come first, and that's ok.

Cystic Fibrosis Trust

Helen Barrett
Bright Ideas Winner

The 2026 Helen Barrett Bright Idea Awards are now open. The closing date is Sunday 11 October. Find out more and apply at **cysticfibrosis.org.uk/awards**

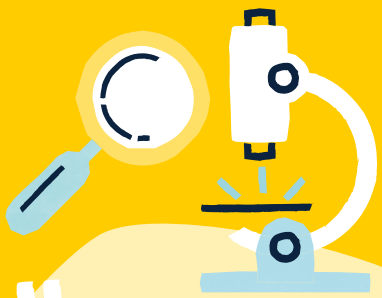
You can follow Fairytales and Tiaras on social media at **@fairytalesandtiarasuk**

Cystic Fibrosis Trust

Be part of every breakthrough

Join our community of monthly givers and help make sure the vital research and support that changed Catherine's life is there for everyone who needs it.

Sign up to give regularly at **cysticfibrosis.org.uk/gift** or call **020 3795 2177** to sign up by phone or request a paper form.



"In the future, I hope that everyone with CF will be able to benefit from modulators and that treatment options continue to improve. Regular donations to Cystic Fibrosis Trust can help get us there."

Catherine, who has CF

Uniting for a life unlimited