

Cystic  
Fibrosis Trust

# CFLife

Issue 20

[cysticfibrosis.org.uk](http://cysticfibrosis.org.uk)



## **Your stories**

Sharing experiences of male fertility and CF

## **In focus**

New research into CF diabetes

## **Ask the expert**

Money-saving tips

Uniting for a life unlimited

# Welcome!

People affected by CF work in a wide range of jobs and careers, bringing their own unique talents, skills and experience to the workplace. Our feature on work and CF (page 4) shares the workplace experiences of Dom, Jane and Charlotte – and some of the transferable skills that CF has helped them to develop.




We're excited to share some brand new features in this issue, including **Ask the Expert** on page 12, featuring our own Welfare Officer, Rachel, who is answering your questions on managing finances when you have CF. Our new **We are all #TeamCF** feature (page 10) spotlights some of our incredible supporters and has inspiration for those of you who'd like to get involved in fundraising this year. And **Pass the mic** on page 26 showcases the wonderful creative talents of those in the CF community – this month we hear from Willow about their leap into stand-up comedy.

Elsewhere in this edition, we hear from Dan, Sean and Matthew about their experiences of fertility and CF (page 14). We go inside the lab with Trust-funded researchers Dr Ildem Akerman and Prof Vicky Salem (page 8) to learn about their research into diabetes and CF. Plus, we spotlight our new resources on nutrition (page 20), which cover everything from nutrition and pregnancy, to teaching children to swallow enzymes.

We hope you enjoy this latest issue, 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

-  @cysticfibrosis.org.uk
-  Cystic Fibrosis Trust
-  forum.cysticfibrosis.org.uk
-  cftrust
-  @cftrustuk

## Useful contacts

### Donations

020 3795 2177

[supportercare@cysticfibrosis.org.uk](mailto:supportercare@cysticfibrosis.org.uk)

### Events and fundraising enquiries

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### Cystic Fibrosis Trust Helpline

0300 373 1000

[helpline@cysticfibrosis.org.uk](mailto: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 our new address:**

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Cystic Fibrosis Trust, 33 Creechurch Lane,  
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[magazine@cysticfibrosis.org.uk](mailto:magazine@cysticfibrosis.org.uk)

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**Uniting for a life unlimited**

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Willow's leap into stand-up comedy



**On the cover:** Sean, who features on p14

**This page:** Top; Willow, who features on p26

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



# Know your worth

Expert organisers, problem-solvers, communicators... people with CF have many skills that are valuable to employers. We chat to Dom, Jane, and Charlotte about how CF has shaped their careers and the transferable strengths they bring.



**Jane worked for the Department of Work and Pensions (DWP) for over 30 years and was awarded an MBE in 2003.**

I started at the DWP in 1981 and worked there for over 34 years. With hindsight, I wish I'd told colleagues about my CF earlier, but back then life expectancy was still short, and I didn't want to be treated differently. Advances in care enabled me to carry on working until my early 50s.

Living with CF has given me lots of transferable skills, like communication skills. I learnt to discuss complex issues with medical teams from a young age – friends would say our clinic conversations sounded like doctor-to-doctor briefings. As an inpatient, I chat with everyone from cleaners to clinicians, and those communication skills are very useful at work.

CF also brings practical problem-solving; if your needle stops working on a Friday evening, you have to change your routine to get it sorted. And we also learn to understand complicated instructions, like how to mix IVs and administer them, manage drug side effects, and have great time management skills to fit everything in our normal day. Most importantly, we know when to act independently to solve our problems and when we need to seek help – just like in the workplace.

I'm a great believer in using our CF experiences in the world of work. It's about finding examples that show employers you're the right person for the job. I know work isn't an option for some people, but for me it has made a real positive difference to my life.



**Dom is a Helpline Support Officer at Cystic Fibrosis Trust. He's previously worked in logistics and teaching.**

I've worked since I was 22, apart from a break to have my lung transplant. I'm now in my 38th year of work, although now I work part time.

Today, you don't have to tell an interviewer that you have CF – you have stronger protections under the Equality Act 2010 – but early on in my career, I lost a job offer when a required health assessment revealed my CF, which I hadn't disclosed. It was a knockback, but it made me more determined.

From my experience, these are some of the unique transferable skills that people with CF can bring to the workplace:

- **Handling complex information:** Many adults with CF learn to follow clinical instructions, like physiotherapy techniques or managing home IVs. This is just daily life for many of us with CF, but these are skills that require attention and technical understanding.

- **Adaptability:** CF and work both often throw up unexpected challenges – infections, inpatient stays, short deadlines! I've learnt to adapt quickly and pragmatically to changing situations.
- **Time management:** Meeting the heavy treatment burden, exercise regime, and nutritional requirements of CF demands good time management and strong self-discipline.
- **Empathy and perspective:** Having CF has given me a valuable perspective on life and helped me to understand others' challenges. Working on the Helpline has opened my eyes to a lot of different experiences others with CF have had to contend with. I feel I can more naturally empathise with vulnerable people as a person with CF.
- **Resilience:** I often joke that supporting Birmingham City has helped me cope with setbacks and unhappiness! CF presents its fair share of challenges, but I've always bounced back, both in and out of work.

## Charlotte works in HR and has experience supporting people in employment.

Living with CF can present unique challenges, especially when it comes to employment. Balancing work with medical appointments, scans, and blood tests is demanding. My health is my most important priority – when you're well, you can contribute effectively.

Before the COVID-19 pandemic, I worked five days a week, but I ended up in hospital a lot more because I was always exhausted. I moved to a four-day work week to better manage my health.

The pandemic and treatments like Kaftrio have helped me reassess my work-life balance; working four full days lets me stay productive and healthier.

The skills gained from managing CF, like resilience, time management, discipline and acute observation, are invaluable to employers. Don't assume CF puts you on the back foot.



## Work Forwards

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

- one-to-one employment support for people with CF and for carers, covering careers advice, job search, CVs, applications, interviews, and workplace issues
- **Career Flavours** webinars where people with CF share their industry experiences
- webinar sessions on different employment topics, from transferable skills to confidence building
- guidance and peer networking for people starting or growing their own business
- video resources about employment rights, including a video to share with employers to help them understand CF
- a chance to share experiences of work and CF through our Employment Stories library, to inspire and support each other.

If you would like support on any aspect of work or employment, please visit **[cysticfibrosis.org.uk/workforwards](https://cysticfibrosis.org.uk/workforwards)** and complete our online form.

# Putting CF diabetes research in the spotlight

Tilly and Joseph are members of Cystic Fibrosis Trust's Youth Advisory Group (YAG) and both live with CF diabetes. They spoke to Dr Ildem Akerman and Prof Victoria Salem about their Trust-funded research project investigating a novel type of treatment for CF diabetes.

## How would this new type of treatment work?

We would take some cells from you, for example cells from a blood sample, make them into stem cells and then into insulin producing (beta) cells in the lab. We'd put the new beta cells back into your body. It sounds simple, but obviously it has a lot of complications! Researchers have been looking at this as a way of treating type 1 diabetes and we're hopeful it could work for people with CF diabetes too.

## How would the treatment be given?

There are still a lot of unknowns about how such a treatment would be given. What might happen is that you would donate blood, come back six months later and receive the lab grown cells as an implant. We think this would be an implant into the muscle in the front of your tummy.



Prof Victoria Salem



Dr Ildem Akerman

## What are the next steps for this research?

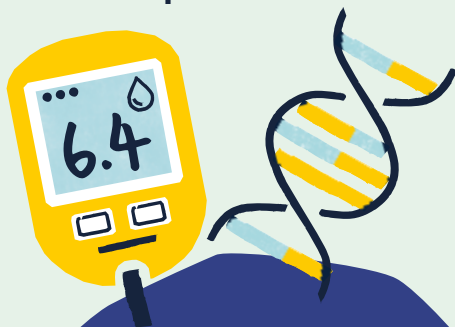
There are still a lot of questions to answer about this type of treatment and we won't find out all of the answers by the end of this project.

The first step is to make sure that this is a feasible approach for people with CF diabetes. For example, does the faulty CF gene/protein change how to make stem cells, or how to make beta cells from stem cells?

After that we need to make sure we can grow medical-grade cells for implant, for example growing them at scale and ensuring they have no viruses etc.

Then researchers can begin testing the safety of this type of treatment.

## More than *four in 10* people with CF will develop CF diabetes



“You never even learn about CF diabetes in school. It's just like there's two types: type one and two. I've never really heard about much CF diabetes research either.”

Joseph

“Thank you. For people with CF, diabetes does get pushed to the side in favour of other symptoms and complications of CF. So it's nice someone is looking out for it.”

Tilly

You can find out more about this new research at [cysticfibrosis.org.uk/diabetesresearch](https://cysticfibrosis.org.uk/diabetesresearch)

# 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.



Harold

## Harold

Harold and his wife became very proud grandparents to Harry when he was born in April 2025. Following the routine newborn tests, Harry was diagnosed with cystic fibrosis a few weeks later.

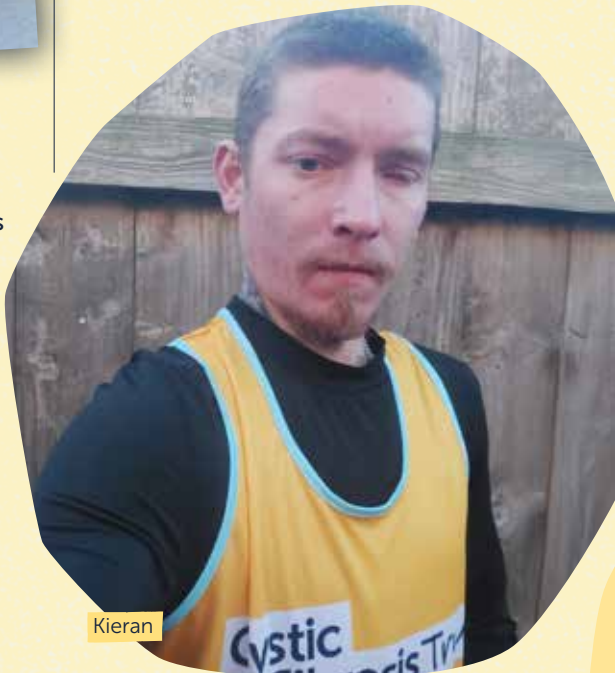
**"This came as a massive shock to all of us, especially as we had little to no understanding of the condition and what this actually meant,"** says Harold.

Inspired to do something that could help both Harry and other families affected by CF, Harold decided to organise and host a charity golf day in aid of the Trust, which will be taking place in Edinburgh later this year.

## Kieran

In 2025, Kieran was very ill; his lung function dropped to 20% and he was placed on the transplant list. However, with support from his wife, family and CF team, Kieran regained lung function and continued his passion for fitness to ensure a continued recovery.

**"The reason I am taking part in the Great North Run is because I want to help raise money for CF research and support that changes lives."**



Kieran

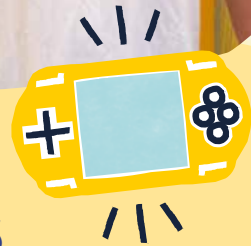
## TeacherActive

TeacherActive have supported the Trust for 10 years and are passionate about making a difference to as many people as possible. The team sadly lost a colleague and friend in 2017 who had CF, so their fundraising is incredibly personal to them. They run several events each year, across their teams and offices around the UK, including challenges and competitions.



## Now it's your turn!

Visit [cysticfibrosis.org.uk/teamcf](https://cysticfibrosis.org.uk/teamcf) and see what's coming up in 2026 and sign up to make a difference. Can't find anything you like? Why not organise your own event? Speak to our team at [events@cysticfibrosis.org.uk](mailto:events@cysticfibrosis.org.uk) to get started.



## Events for 2026

**26 April** – London Marathon (and applications for 2027 will open soon afterwards)

**23–24 May** – Edinburgh Marathon Festival

**12 June** – Wear Yellow Day

**8 July** – International Video Game Day... **#Game4CF!**

**13 September** – Great North Run, Newcastle

**4 October** – Cardiff Half Marathon

**11 October** – Royal Parks Half Marathon, London

**15 December** – Carols by Candlelight, London





## Ask the expert

Our Welfare Officer Rachel answers some frequently asked questions around managing finances when you have CF – from practical budgeting tips to reducing your household bills.

### What can I do if I'm struggling with debt?

Debt can build up quickly when managing a long-term health condition like CF, especially during periods of ill health or reduced income. If it feels unmanageable, you're not alone and support is available.

Contacting our Helpline or your CF social worker is a great first step to ease the pressure. Don't worry, getting help won't usually affect your credit rating, it's an opportunity to take control and plan ahead.

We'll explain your options clearly and help you decide on a realistic plan, whether that means working in partnership with a debt adviser, talking

to creditors, arranging affordable payments or considering formal solutions if that's best for you.

### What is a budget and why is it helpful?

A budget is a simple plan that helps you keep track of what money is coming in, and where it all goes.

Using the **Income Maximisation Service** is a great way to start your budget. Together, we'll explore ways to boost your income, identify unnecessary spending, and spot areas where small changes could free up cash.

Budgeting doesn't have to be complicated; try a handwritten list, an easy-to-use app, or an online planner to get started.

Budgeting can also help prepare for unexpected costs like hospital stays. Many people find budgeting reduces stress and gives a sense of control. And remember – be kind to yourself! Don't get disheartened, reach out for help to get you back on track.

### Why do I feel anxious or overwhelmed when dealing with money?

Money worries often come with feelings of anxiety because they're closely linked to security, independence, and wellbeing. Limited income and rising costs can all feel out of our control and overwhelming at times. Living with CF often means juggling uncertainty, extra costs, and fluctuating health, which can make keeping track of bills and budgets even harder.

Breaking things down into small, manageable steps can help.

Support can make a real difference too. Speaking to advisers who understand the financial impact of CF will help you feel less alone and give you practical steps to regain a sense of control.

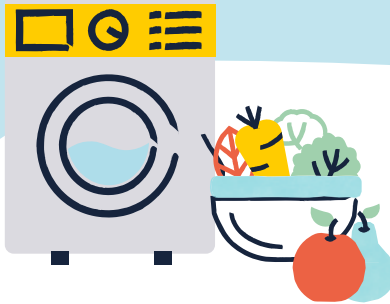
If you'd like to find out how our **Income Maximisation Service** can help you, get in touch with our Helpline.

Call **0300 373 1000** or **020 3795 2184**, Monday–Friday 10am–4pm

Email **helpline@cysticfibrosis.org.uk**

Chat with us on **Facebook** or **Instagram**

Message us on WhatsApp on **07361 582053**



### Here are my top tips to cut bills:

- **Check your deals:** Switching energy, broadband or mobile providers can lead to immediate savings.
- **Join the Priority Services Register:** It's free access to extra support from energy and water companies, and in some cases more suitable tariffs.
- **Cut water costs:** Switching to a water meter can lower bills, and if you receive certain benefits and use more water because of CF, the WaterSure scheme could save you money.
- **Save energy:** Maintain comfort and cut energy costs. Use energy-efficient bulbs, turn appliances off at the plug, use draft excluders and reflective radiator sheets.
- **Use it or lose it:** Review streaming platforms, app subscriptions, and memberships regularly.
- **Spread the cost:** Ask your local authority to pay Council Tax over 12 months instead of 10 for easier budgeting.



Sean and his daughter

## **“I want to help other men going through the same thing”**

**Around 98% of men with CF are unable to father children naturally because the tube that carries sperm (called the vas deferens) is missing or blocked. Their sperm is usually healthy – it just can’t travel through the blocked or missing vas deferens. It may still be possible for men with this CF-related problem to father biological children through fertility treatment.**

**We know fertility can be a difficult and emotional topic to talk about, so in this issue of CF Life, we hear from Dan, Sean and Matt about their experiences – and why they wish there was more awareness of this aspect of cystic fibrosis.**



Matthew

### Sean's story

I met my partner Anna in my 20s and I had a fertility test not long after, which confirmed I wouldn't be able to father children naturally due to my CF. I had hoped having this test done early might make the process quicker later down the line, but I had to have another one later on because of living in a different region. Things like this can make navigating the system really hard and there was confusion and delays throughout.

I also felt quite uninformed about fertility. There's a lack of awareness around this topic, and I think there needs to be more done to educate men with CF and CF teams.

Eventually we started IVF, and we got four fertilised embryos that resulted in a pregnancy which was amazing. Seeing the heartbeat of my daughter was indescribable and there was an overwhelming sense of relief that I hadn't anticipated. When she arrived, it was just the best feeling.

My advice to other men with CF who are going through this process is to try and get the ball rolling as early as you can. Talk to people: your community, friends and family. Don't be afraid to ask questions. And keep the faith!

### Matthew's story

We're about to start IVF, but it's been a very long process to get here. There isn't always the specialism in CF teams to be able to talk about this topic and it wasn't easy to access the information I needed.

Navigating the NHS has been like navigating a maze, and there have been barriers every step of the way. We were told we had to wait 80 weeks for an appointment for treatment on the NHS. In the end, we were pushed to go private. We are of course privileged that we can do that, but there'll be many people out there who won't be able to.

I feel that there should be some kind of protocol that means men with CF are having discussions with their CF teams about fertility at an earlier age.

It's been a really challenging experience for me and my partner and very emotionally draining. I hope that there can be more awareness around this symptom of CF and I'm passionate about sharing my experience to help other men going through it.



Dan



### Dan's story

I have two daughters. My eldest daughter was conceived through IVF and my youngest is adopted.

When me and my wife started fertility treatment it was very stressful and there were a lot of ups and downs. Starting a family should be a lovely and enjoyable experience, but just the nature of it makes it feel very medicalised. You can't help but blame yourself and there's a lot of guilt there as you feel the responsibility of it.

You feel quite disconnected from your CF team when you're going through the treatment; you're referred on to a completely different service that obviously doesn't know you or anything about your CF. It felt quite isolating and, particularly for men, there didn't seem like there was much support out there.

Adoption was a mostly positive experience, but there were some concerns around my health and how it might impact the assessment process.

### 35 men with CF became fathers in 2024

We actually had a negative conversation with a provider about this, and it put us off for a long time. But in the end my health didn't affect the process at all.

I feel incredibly lucky to have my family of four and privileged that I'm well enough to spend time with them, as there were times before Kaftrio when I worried how long I'd be around to see them grow up.

#### We're here to support you

If you have questions about fertility, please get in touch with your CF team or our Helpline.

We're currently updating our information on fertility and CF, please keep an eye on our website for more information coming soon.

# Celebrating the life of a loved one

Tribute fundraising can turn grief into action. Tribute pages celebrate the life of a loved one while creating lasting impact – funding vital CF research, supporting other families affected by CF, and keeping the memory of loved ones alive.

At the start of 2025, Anna decided to honour her sister Rachel by raising funds for people with cystic fibrosis. Friends and family joined her for the Forth Road Supernova and brought their efforts together on a tribute page for Rachel. So far they've raised over £4,500, and more fundraising is planned. Anna says the tribute **"highlights a life that was lost when Rachel still had so much to give,"** and that understanding how tough Rachel's medical challenges were motivates them to support research and other families living with CF.

To create your own tribute page, visit [cysticfibrosis.org.uk/tribute-funds](https://cysticfibrosis.org.uk/tribute-funds), or contact our In Memory Officer, Susan, at [susan.jackson@cysticfibrosis.org.uk](mailto:susan.jackson@cysticfibrosis.org.uk)

**"Rachel still had so much to give"**





## What's on your mind?

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

We have some damp and mould in our home. We rent from a housing association and live in England. We've raised this with our landlord but they just paint over it. They've also tried to blame us for the problem – we've done everything that they've asked to stop it coming back, but it has got a lot worse this winter. Our CF team are helping. We don't want to live this way. What can we do?

### Matthew's answer:

I'm sorry you're dealing with this – living with persistent damp and mould is stressful when someone in your home has cystic fibrosis. It's good that your CF team are supporting you, and you're right to expect a safe, warm home where treatments and daily life aren't made harder by the condition of the property.

A safe home matters for health. Damp, mould and poor ventilation can make breathing harder, increase infections, and get in the way of treatments, so it's important these problems are taken seriously by your landlord. In England **Awaab's Law** is being introduced in phases and sets clear timescales for social landlords to inspect and make safe hazards in the home.

From 27 October 2025 if a hazard is classed as significant damp or mould, or an emergency hazard, the landlord must investigate and make the situation safe within a set timeframe. If your landlord isn't acting, you can ask your local authority for an inspection under the **Housing Health and Safety Rating System (HHSRS)**.

An environmental health officer can visit, assess the risks, and require your landlord to act if the home is unsafe. Keep a record of your communications, photos of the problem, and any advice from your CF team – that evidence can help when you ask for an inspection or need to show the risk to health.

We've updated our **housing page** with more practical information and a downloadable **template letter** that explains the specific risk damp and mould pose to someone with CF. That letter is written to help you make the case clearly to your landlord or council, and you can adapt it to include your own details and any support your CF team has provided.



If you are not happy with the way your landlord is responding to your concerns, you can raise a formal complaint. For help with landlord complaints, you can contact the **Housing Ombudsman Service**.

For more support or information, please contact **0300 373 1000**, **helpline@cysticfibrosis.org.uk** or message us on WhatsApp on **07361 582053**.

Living with cystic fibrosis can mean extra costs and money worries. We provide a range of grants for people with cystic fibrosis and their families, support for those applying for benefits and information about prescription charges. Visit **cysticfibrosis.org.uk/financial-support** to find out more.



## New appeal launched to fund vital services

Our Helpline and support services are a lifeline for many people affected by CF. Please donate to help make sure Matthew and the team can be there to answer people's toughest CF questions.

Visit **cysticfibrosis.org.uk/listen** or scan the QR code to make a donation today. Thank you.





## CF and nutrition

We've recently updated our resources on diet and nutrition with support from dietitians in the British Dietetic Association (BDA) Cystic Fibrosis Specialist Group. Jess from our Information Team explains more.

### How has the changing CF landscape shaped the updated diet and nutrition resources?

There have been a lot of changes to CF over the last few years, in part this is due to advancements in modulator therapies, but also other treatments and new areas of research. Because of this, the way diet is managed for people with CF has changed too.

At Cystic Fibrosis Trust, we've got over 20 leaflets about nutrition topics, ranging from weaning to exercise nutrition and much more in between. We've been going through these resources with health professionals and people with CF to make sure they are up to date and provide the information that you need. Some have undergone larger updates than others and some will be completely new.

### What resources have we made updates to?

The following have been updated and are already live on our website:

- enzyme refusal in children
- teaching your child to swallow enzymes
- food refusal in children
- nutrition and pregnancy
- exercise nutrition
- staying hydrated
- iron in the CF diet
- salt in the CF diet
- vitamin supplements in CF
- post transplant nutrition
- alcohol and CF.

You can find all these resources by visiting [cysticfibrosis.org.uk/nutrition](https://www.cysticfibrosis.org.uk/nutrition), or scanning the QR code at the end of this article.



“ We hope these updated factsheets provide clear, practical information, while reinforcing the importance of individual, tailored advice for everyone living with CF.”

CF dietitians who have been working on our nutrition resources



### What's next in the pipeline?

We will soon be releasing our new GI (gastro-intestinal or gut health) factsheet. We now know more about gut symptoms and how they can impact the daily lives of people with CF. Because of this, the GI nutrition factsheet has been updated to give clearer, more practical information for both people with CF and the health professionals who support you. The updated factsheet uses emerging evidence to help people with CF and their CF team to better understand and manage your gut health.

CF dietitians have also told us that they are seeing changes in the way that we think about body weight in people with CF, due to the impact of modulators but also many other factors. For many people with CF, gaining weight is no longer the main focus of their nutritional intake. Everyone living with CF should be supported to maintain what is a healthy weight for them and some would like to reduce their weight. Because of these changing needs, we are producing information sheets for those looking to lose, maintain or gain weight. The emphasis will be on eating for health and what is right for the individual.

We want to approach this topic in an open and sensitive way. We are looking for people with CF who have an interest in this topic to help us develop these resources. If you are interested, please reach out to [infoteam@cysticfibrosis.org.uk](mailto:infoteam@cysticfibrosis.org.uk)

Scan this code to access all our resources on nutrition and CF.





“ Training has been challenging but incredibly rewarding. Some days I feel unstoppable; other days, it’s tough.”



## On your marks

Thanks to incredible advances in CF treatments, record numbers of people with cystic fibrosis are now able to take part in our endurance challenge events, with 29 signed up to the London Marathon this month – our highest number ever. For Justyna, 27, running a marathon seemed like a distant dream for much of her life, but now it’s a reality. She shares her story and reasons for running.

I'm Justyna, a girl who smiles a lot and, most recently, a nursing student. I was diagnosed with CF at six months old. Life started with challenges: I was born prematurely, and from my very first days, I had to fight.

Living with CF is a constant balancing act – managing appointments, treatments, hospital stays, and potential surgeries while trying to live as normal a life as possible. Over the years, I've learned resilience, patience, and how to find strength even when things feel overwhelming. I'm proud of how far I've come.

Running is something I never imagined I could do, so reaching the point where I can run a marathon feels incredibly special. It wouldn't have been possible without the advancements in treatments that, just a few years ago, we could only dream about.

Training has been challenging but incredibly rewarding. Some days I feel unstoppable; other days, it's tough. Managing my health alongside a training schedule isn't easy, but I'm making progress! I've cried, struggled, and had setbacks, but I haven't – and won't – give up. On the days when training does get tough, I think about the CF community and why I started this journey.

## Marathon tips for people with CF

We've worked with exercise physiologist Dr Owen Tomlinson, physiotherapist Rachel McDowell and running coach Matt Strange (who has CF) to put together a guide designed to support you every step of the way when taking on a marathon. From managing your symptoms to tailoring your training routine, we've got practical tips and advice to help you run safely and confidently. Read the guide at [cysticfibrosis.org.uk/marathontraining](https://cysticfibrosis.org.uk/marathontraining)

I'm a first-time runner – someone who never thought running was possible. Every step is for a future where CF doesn't limit anyone's life.

Cystic Fibrosis Trust has had a huge impact on my life, and on the lives of so many others with CF. They help people with CF live longer, healthier lives and this run is my way of giving something back.

To know that a record number of people with CF will be taking part in the marathon this year is incredible and inspiring. It shows how far we've come but we can't stop there. The breakthroughs have been amazing and changed lives, but there's still a long way to go until everyone with CF can live a life unlimited. A life of freedom and the ability to dream big without worrying about CF holding you back. A life where you don't have to plan everything around treatments and hospital stays. A life lived without constant compromises.

**We'd like to wish Justyna and all our London Marathon runners lots of luck and thank them for their incredible support. We know that running is not for everyone, and we have many different ways you can fundraise for Cystic Fibrosis Trust – from treks to quizzes, bake sales to game-a-thons. Visit [cysticfibrosis.org.uk/TeamCF](https://cysticfibrosis.org.uk/TeamCF), or get in touch with our team at [events@cysticfibrosis.org.uk](mailto:events@cysticfibrosis.org.uk) to find out more.**



**Scan the QR code to find out more about our marathon training tips**

# Book club

Polly Crosby is a writer with cystic fibrosis. Last year she released her novel **The Vulpine**, which was inspired by her own experiences of living with a chronic illness. Budding writers Ella and Rosie, who have CF and are part of our Youth Advisory Group (YAG), interviewed Polly about the book, what she hopes young people with disabilities will take away from it, and her top writing tips.

## Rosie: What inspired you to write **The Vulpine**?

I've written all my life, but I never really wanted to write about CF because as much as it is a part of us, it's a small part of us, right? But then COVID-19 happened and suddenly the whole world was having to deal with the things that we have to deal with – face masks, social distancing, coughing. I thought, actually, maybe I need to talk about my experience of having a chronic illness.

There weren't many books when I was your age that dealt with that in a way that was uplifting or powerful. It was all about a sob story. I felt like this was the right time in my life to talk about it.

## Ella: When you were writing, did you find it hard or easy to put the experience of living with CF into words?

I think the lovely thing about writing **The Vulpine** was that I never used the term 'CF' because I didn't want to label Ora, and that felt quite freeing. It then felt as if I was able to separate it slightly from me. It was really cathartic to write these things down and it was interesting to think back to how I felt at that age about my condition.



Polly

**Ella: What do you hope young people with disabilities will get from this book? And what do you hope young people without disabilities will take away?**

I hope that for people living with a disability this book will feel positive and make them realise that they're not alone in this world.

For others, I hope they can realise that just because you don't see something, it doesn't mean it's not there. And just because many of us hide it very well, it doesn't mean that there isn't a lot going on under the surface.

**Rosie: What advice would you give to budding writers like me and Ella?**

I would say write as often as you can. It doesn't have to be for hours. I quite often find 10 or 20 minutes of writing every day is better than big chunks every few weeks.

My other advice is don't go over the same thing again and again. If you've written a paragraph and you go and start polishing it and trying to make it better, you'll never carry on. Whatever idea you have, whatever you want to write, get the whole thing out!



Ella

**Ella: How long have you been writing for and what got you into it?**

I've been writing forever and I clearly remember writing a poem about a mermaid when I was about seven.

I started university at 18 to train to become a teacher but couldn't continue because I was too unwell – there weren't the CF treatments that there are now. It made me think, what do I want to do with my life? So I started writing a novel. Some people are lucky and get published straight away. I waited 20 years for my first publishing deal, but none of that time was wasted because I was honing my craft. Writing, for me, is like breathing. It's so important. If I can't write I'm not happy, so I just knew I had to keep going.

If you'd like to find out more about our Youth Advisory Group (YAG), visit [cysticfibrosis.org.uk/YAG](https://cysticfibrosis.org.uk/YAG)

You can follow Polly on Instagram [@writerpolly](https://www.instagram.com/writerpolly)



Rosie



## Finding the funny

Comedy has always been a way for Willow, who works as an animator, to make sense of life – from growing up with cystic fibrosis to embracing their gender identity. As Willow prepares to take a leap into stand-up, they share how humour has helped them.

### My CF journey

I was diagnosed with cystic fibrosis a couple of weeks after birth through the heel prick test. From that point on, my parents were really on top of all the treatments and it helped that my mum was a neonatal nurse and so already in that world. I was raised with a diligent outlook on treating but she would say: “CF fits around our life, we don’t fit our life around CF”.

I was relatively healthy as a child and didn’t get admitted for IV antibiotics until I was about 11, and then from that point I was in and out of hospital and that became routine.

In 2018 I started taking Kaftrio on a clinical trial, and haven’t been admitted to hospital since 2017, or needed oral antibiotics.

Kaftrio has been amazing, but it hasn’t solved everything. I don’t know if I’m in the category of people who need intervention to have children, and there are lots of other possible complications of my CF that might need attention in the future. There’s still people who can’t benefit from modulators, and who have side effects, and other people have things like antibiotic hearing loss which isn’t suddenly going to be fixed. CF still needs as much attention as it did before modulators.



“ I love the idea that I could inspire another person with CF to try their hand at something like comedy. My advice to anyone thinking about it is just to try it.”

### Following my passion

I've always loved stand-up comedy and shows like *Mock the Week* and *Live at the Apollo*. I did a stand-up comedy course in 2018 – I'm someone who always likes different side quests – and that further sparked my interest. It became a way to process my life with CF and my gender identity. Really tragic aspects of life or things that are difficult to deal with are perfect fodder for comedy: if you don't laugh, you'll cry!

I've been gigging more regularly and really enjoying it. I even recently won the G&B New Act Competition in London. I talk about my trans experience as well as my cystic fibrosis and feel like there's things that people can take away from my sets as well as laughter. With CF, it's about wider

knowledge and awareness, and with being trans, it's about educating people and showing that we exist; I'm here on this stage despite the backlash that we sometimes receive. I feel empowered when I'm on stage. When I feel in command of people's laughter, that feels amazing.

I love the idea that I could inspire another person with CF to try their hand at something like comedy. My advice to anyone thinking about it is just to try it. You might absolutely bomb, but that's okay, because there'll probably be one or more jokes that work and you can keep. Just keep flexing that creative muscle by writing all your comedy ideas down and try and do them on stage, even if you don't feel ready – here's a secret: nobody's ever ready!

Do you have a creative hobby or passion you'd like to share in the magazine? If so, get in touch with us at [stories@cysticfibrosis.org.uk](mailto:stories@cysticfibrosis.org.uk)



## We're here for *you*

In 2024/25, our Helpline service handled over 4,550 enquiries from people affected by cystic fibrosis, providing practical support, information and a listening ear when people needed it the most.

If you need support, you can contact our friendly Helpline team Monday–Friday, 10am–4pm, by phone, email, WhatsApp or on our social media channels.

- [Helpline@cysticfibrosis.org.uk](mailto:Helpline@cysticfibrosis.org.uk)
- Phone **0300 373 1000**
- Whatsapp **07361 582053**

Whatever you're dealing with, you don't have to face it alone.