Cystic Fibrosis Trust

Issue 13

cysticfibrosis.org.uk

CF Life

Your stories
CF awareness through drag

Focus
Coping with the cost of living crisis

Feature
Explaining CF to children

Uniting for a life *unlimited*

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Issue 13 – August 2022

If you'd like to give us feedback on this issue, or have ideas for what you'd like to see in the magazine, email us at **magazine@cysticfibrosis.org.uk**

On the cover: Jordy, who features on p14
This page: Lucy Baxter, who features on p24-25

Social

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

Useful contacts

Donations
020 3795 2177
supportercare@cysticfibrosis.org.uk

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.

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Welcome to CF Life

In this issue of CF Life, we spotlight our Clinical Trials Accelerator Platform (CTAP) and the opportunities it presents for people with CF to access the newest treatments being developed. We also give you a behind the scenes look at the making of our new children's animation and chat to some of the amazing young people with CF who have helped co-produce it.

Following the launch of our Cost of CF report, which painted a shocking picture of the financial burden many in the community are facing, Sangeeta and Nicky from our Welfare Team provide some practical tips to help people with CF in these challenging times. And we're pleased to introduce our new feature, 'What's on your mind?,' in which Matthew from our Helpline team will be answering some of your pressing questions about CF.

Elsewhere in this edition, we hear from Jordy – this issue's cover star – about their amazing career as a drag star. We also meet some of our Team CF London Marathon runners ahead of the big race in October. Plus, Sophie Whiteley, CF Trials Coordinator at the Royal Devon and Exeter hospital, tells us more about an exciting new CF research study called the CF BioResource project.

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

The CF Life team

Uniting for a life unlimited

In case you missed it

Campaigning

In spring 2022, the Trust surveyed people with CF, and their families and carers, about how they experience the cost of CF. The answers you gave us have provided powerful insights into what it is like to live with a long-term condition during a national cost of living crisis.

The results from the survey painted a shocking picture, with 87% of people who responded telling us that they were worried about the cost of living. We aim to use your stories to lobby the Government to make meaningful and lasting change to alleviate the cost of living with cystic fibrosis. Find out more at **cysticfibrosis.org.uk/costofcf**.

Research

Aminoglycosides are a type of antibiotics which are very effective against infections. They are associated with low rates of antibiotic resistance. However, aminoglycosides can cause hearing loss, with researchers estimating that up to 50% of adults with CF could be affected.

RNID and Cystic Fibrosis Trust have teamed up to fund a vital research project to prevent hearing loss caused by aminoglycosides. The £210,000 research project will run for three years. Find out more on our website at **cysticfibrosis.org.uk**.

Care

We're delighted to be able to share the first findings from our patient-reported experience surveys, which offer CF centres insights into what people with CF and their families think about the health care they receive.

Overall, we found that the CF community were highly satisfied with the care they received, with many respondents praising their CF teams. However, we also found that there is an urgent need for more mental health and social worker support. The Trust aims to campaign to ensure all people with CF have the support they need, when they need it.

You can read the full reports at **cysticfibrosis.org.uk/qi**.

Support

We're really excited to tell you about Work Forwards, a brand-new programme of employment support for the CF community.

Work Forwards will provide people with CF with tailored, one-to-one support from a skilled advisor to help you identify and reach your career goals.

This support will also be available to parents and carers of people with CF who want support to find the right balance between employment and caring responsibilities.

Work Forwards will officially launch in the next few months –we can't wait to work with the community to support as many people as possible on their employment journeys. Keep an eye on our website and social media for news of the official launch coming soon, and if you'd like us to contact you to let you know more, email **workforwards@cysticfibrosis.org.uk**.

Fundraising

We would like to say a huge thank you to retired athlete Roger Black, actor Tristan Gemmill, and comedian Chris McCausland for their recent television appearances for the Trust.

Trust ambassador Roger and Coronation Street actor Tristan both appeared on Celebrity Pointless, while Chris took to the hot seat on Celebrity Mastermind, with grunge band Pearl Jam as his specialist subject.

We're extremely honoured and grateful to Roger, Chris and Tristan for using their impressive general knowledge to raise money and awareness for the Trust!

You can watch both Pointless and Mastermind at **bbc.co.uk/iplayer**.

Chris McCausland on Celebrity Mastermind. ©BBC

Clinical trials and you

From developing CFTR modulators and antibiotics to new physio techniques, clinical trials play a vital role in helping ensure people with cystic fibrosis can access the newest treatments being developed.

In 2017, we launched the Clinical Trials Accelerator Platform (CTAP) and the CF Trials Tracker database with the aim to create more opportunities for the CF community to take part in clinical trials. Five years (and over 1,000 trial recruits) later, we look at how these platforms have changed the CF research landscape, and speak to people from the CF community about their experience and motivations for taking part in CF research.

Why are clinical trials important?

Clinical trials are a fundamental part of the process to develop and bring new medicines to people with CF. All new medicines have to be investigated in carefully designed clinical trials before they're made available on the NHS for prescription.

Clinical trials are research studies. They involve participants giving their consent to take part in a trial to potentially receive a new treatment for the duration of a trial. During a trial, researchers will carefully monitor the health of trial participants to make sure the new treatment is having the desired effect and is also safe.

Without clinical trials, even everyday medicines like paracetamol or ibuprofen wouldn't be available for us to use.

Why take part in research?

Taking part in research can be a rewarding experience for many people. In some instances, it offers people the chance to access potentially life-changing new treatments many months or even years before they are available on the NHS. In recent years, clinical trials have given many people early access to CFTR modulators like Kaftrio.

Of course, taking part in a trial doesn't guarantee that you will receive a new medication, and as we know, not all new medications work for everyone.

But there can be other benefits of taking part too. For some people, being a part of a research study is helpful to find out more about their health, since the extra clinic visits and additional investigations can provide a richer insight into what's going on with your own health.

> **"Having the opportunity to have that medicine at such an early age, it really has made a difference."**
>
> Leanne, parent of a child with CF

On a wider level, volunteering to take part in research is not only potentially helping yourself, but it can benefit others in the community too, by allowing new treatments to be thoroughly investigated for safety and effectiveness and helping to bring positive changes to routine clinical care.

> "There's something empowering about making some positive decisions for yourself and feeling that you're part of a potential solution."
>
> Stuart, who has CF

What's it like taking part in a clinical trial?

Candice, who lives with CF, shares her experiences of using the CF Trials Tracker and what taking part in a clinical trial was like.

"When I first heard about the CF Trials Tracker from my CF clinical care team, I went onto Cystic Fibrosis Trust's website to browse the Trials Tracker and found a few trials I was interested in. I had a look at these trials to see whether they were running at my centre, and one was. I got in touch with my consultant and spoke about the possibility of taking part in the trial. One of the clinical research nurse specialists then got in touch with me to discuss the trial in more detail and help me decide whether I wanted to take part.

"It was easy taking time off work to participate in the trial as I had an understanding employer. The trial team paid for my travel expenses and meals while attending trial visits, which also helped with making it easier to take part.

"I enjoyed building relationships with a different team of people apart from my usual clinical team. The research team were all lovely and I knew anything of importance was being fed back to my usual clinical care team. They checked up on me throughout the trial process and were on hand whenever I had questions or concerns.

"I felt like I was able to contribute something positive toward the advancement of treatment for people with cystic fibrosis. On a personal level, my health was closely monitored during this time, so I felt like my health improved and I had better insight."


Candice


Tiffany and her family

Tiffany, mum of 4-year-old Joseph, who has CF, tells us about her family's experience of travelling 260km to take part in a clinical trial of ivacaftor, which she discovered through the Trust's Clinical Trials newsletter

"Our youngest son, Joseph, was diagnosed with CF from the heel prick test taken soon after birth. Neither of us were aware that we were carriers of the CF gene.

"I remember being terrified when I was sent home with the medication for the first time. We put everything on a whiteboard in the kitchen so that we could check off milk feeds and administer antibiotics.

"I can still vividly remember when we were told that Joseph was pancreatic sufficient. It felt like a small victory.

"Soon after, we signed up to CF START, a trial that's looking at the safest and most effective way to treat infants diagnosed with CF with antibiotics.

"We happened to find out about a clinical trial when we received the Trust's Clinical Trials newsletter. The email featured an article about a trial for the CFTR modulator ivacaftor, which was recruiting children under 2 with Joseph's genotype (G551D).

"We travelled 260km to take part in the trial at Alder Hey Children's Hospital. We would have travelled to the other side of the world if we had to.

"We were very lucky as my husband had sufficient flexibility work-wise to enable us all to travel to all the appointments. Thomas, our eldest, was in nursery and was happy to go on a fortnightly adventure!

"The trial team did everything for us, and I mean everything - hotel, travel expenses, snacks, lunch at the hospital, it was all pre-arranged. We were even met at the hotel on arrival with anything we might have needed at the following morning's appointment. The trial team's coordinator was brilliant and really took away all of the stress.

"We were very excited to meet the clinical trials team at Alder Hey. We had spoken on the telephone a number of times prior to our first appointment and had already been given the chance to ask any questions we had. The team are all experts in their field and we felt very privileged to be receiving the very best treatment on offer for our beloved boy. We met some wonderful people during the trial, most of whom we're still in contact with today.

"To have Joseph's life-changing medication early, and to be a part of a trial to give a little back on behalf of all the families impacted by this condition, was an easy decision for us. The day we heard that Joseph was accepted on the trial was one of the best days of our lives."

How is the Trust supporting clinical trials?

Through the CTAP programme, which we launched in 2017 with the support of the Cystic Fibrosis Foundation, we have brought together a network of 27 NHS CF centres who we have funded with specialist trial coordinators to oversee the running of CF clinical trials in the UK. Our national team of CF trial coordinators also act as a point of contact for the CF community to talk to about taking part in clinical trials, helping people with CF and their families find the right trial opportunity for them.

Collectively, our network of CTAP centres have supported over 40 CF research studies and helped over 1,000 babies, children and adults take part in a clinical trial since CTAP launched.

As part of the CTAP programme, we've also created resources and online information about clinical trials, along with the CF Trials Tracker database. All of this information forms our CF Clinical Trials Digital Hub, a platform which aims to help children, adults and parents learn about, and take part in a variety of clinical trials across the UK.

Our Hub is there to help ensure the UK CF community are at the forefront of new and transformative therapies being developed for CF.

Our CF Trials Tracker database is a unique tool which supports the CF community to keep track of CF trials opening in the UK, while also helping people find the right trial opportunity for themselves or a family member to take part in locally or further afield.

Trials are searchable by age, location, and the type of medication being trialled. Each trial listed on the Trials Tracker includes a summary about the trial, along with information about who can take part and which CF centres are running the study. There is also a contact form for each trial to help put people in direct contact with clinical teams to request more information on taking part in a particular trial. This may be their local team or a team at a different CF centre who are running the trial.

Why is the Trials Tracker important?

The Trials Tracker empowers people with CF and their families to take the lead in finding their own trial opportunities. This means they don't always have to be reliant on their CF team getting in touch. They're also able to find and sign up for trials taking place across the country – so they're not restricted to only taking part in trials at their local CF centre.

How can I find out more?

For more information on the Trials Accelerator and how you can get involved in clinical trials, visit our Clinical Trials Hub at **cysticfibrosis.org.uk/clinicaltrials** or browse upcoming clinical trials on our CF Trials Tracker at **cysticfibrosis.org.uk/trialstracker**.

Together, we can all play a part in the race for effective treatments for everybody with cystic fibrosis.

A CF research study for all

Sophie

In the last few months, CF centres in our Clinical Trials Accelerator Platform (read more on page 6) have been setting up for an exciting new CF research study called the CF BioResource project. We caught up with Sophie Whiteley, CF Trials Coordinator at the Royal Devon and Exeter hospital, to find out more.

Hi Sophie! Can you tell us what exactly the CF BioResource project is?

The CF BioResource project, or to give its full name, the **National Institute for Health Research (NIHR) BioResource – Rare Diseases (CF BioResource Project)** allows people with CF to register their interest in taking part in research, based on their genetic make-up.

That's quite the mouthful! But why is the CF BioResource project so important?

There are a lot of unanswered questions in CF. For example, why are there differences between families and siblings with CF? Knowing more about people's genetics beyond just the CFTR genes might help to understand why some people get side effects with different medicines or why others do really well. Equally, there might be things we can do to minimize those side effects in the future, based on subtle genetic differences. The CF BioResource project may also help us develop new medicines in the future.

Sounds exciting! Who can take part in it?

The CF BioResource project is different to most CF research as anyone can take part, no matter what their lung function is, whether they have an CF complications or other health conditions, or if they've had a transplant. It's really refreshing not to have a long list of inclusion and exclusion criteria to consider when seeing if anyone we look after can take part.

Sophie (left) and Exeter team colleagues

So it really is a research study for all. For those who might be interested, what does taking part involve?

There are two phases to taking part in the CF BioResource project. The first stage is agreeing to become part of a research register and giving a blood sample for genetic analysis. After your blood sample has been processed, then researchers may invite you to take part in future research studies.

Do you tell people with CF about it at their clinic visits?

For me, it starts by looking to see who will be coming into the clinic soon, to send them some information in advance of their appointment.

On the day of their clinic visit, if they agree to take part they'll sign a consent form and then I'll take a blood sample from them. If they're having blood samples taken for other reasons and have consented, then I'll take a sample for the CF BioResource project at the same time.

Where can I find out more about taking part?

Visit the CF Trial Tracker on the Trust's website for a list of centres taking part **(cysticfibrosis.org.uk/trialstracker)**. There's also more information and some videos explaining the CF BioResource on the website too. **(cysticfibrosis.org.uk/bioresource)**

Photo credit: Richard Frew Photography

“There is space for you – sometimes you just have to find it”

Their drag act The Real Housewife of Leith has delighted audiences across the country, as well as raising vital awareness of cystic fibrosis. Now, Jordy Deelight is embarking on a new adventure as a non-binary artist and singer. We caught up with Jordy to hear more about how they balance CF and performing, their hopes and dreams for the future, and the importance of listening to your gut.

Hi Jordy! Can you start by telling us a little bit about yourself?

My name is Jordy Deelight, I’m a non-binary artist, singer and DJ from Edinburgh. My pronouns are they/them, and I live alone like a witch with my two black cats. My main hobbies are yoga, meditating, and spending time with friends – including lots of wine when I’m not working! And I have cystic fibrosis.

What’s your journey with CF been like so far?

I’ve faced many health issues with my CF, but the real problems started when I caught flu in 2017. My health started to go downhill, and I ended up being referred for lung transplant. I spent 2018 until 2020 getting assessed by the incredible team at Freeman’s in Newcastle. At this point I went part-time at work, barely working when in hospital, and I kept losing weight, struggling to walk up hills or dance on a night out. I decided the best way to cope was to document this in my work and use it to channel my frustrations and issues in a therapeutic way. I did a drag show about lung transplants in CF called ***The Honeymoon Period*** in 2020, just before the pandemic, which won an award. It was even praised by the First Minister, Nicola Sturgeon. Then, on compassionate grounds due to me needing lung transplant, I started taking Kaftrio, and my whole life changed.

What difference has Kaftrio made to your life?

The effects of Kaftrio for me were instantaneous. Within hours of the first dose I was clearing my throat and so much mucus (ew, I always squirm saying that word – even at 27!) was coming up. I gained weight quite drastically, and went up three dress sizes – which was brilliant for my cystic fibrosis, but my drag wardrobe needed a good clear out! We went into the pandemic two weeks later, and I was isolating and shielding, so it was like I was given a new car and couldn’t take it out for a test drive.

Kaftrio has also stopped me (for the time being) needing a lung transplant. It’s given my health the reset I needed to explore new and exciting things in my work.

Moving on to your work! Can you tell us about your life as a performer – and how you balance it with CF?

This year marks seven years I’ve been doing drag professionally. It’s going to be the last, as I’m starting to explore a new career as a non-binary artist and singer in 2023. On average, it would take me two hours to get my make up on and transform myself into my old brand as The Real Housewife of Leith. I’ve done some truly wonderful things. I was commissioned by the National Theatre of Scotland to make a short film called ***Dear Deelight***, had my work featured with the BBC, and got to perform alongside a number of celebrities.

Photo credit: Brewhemia Edin

I always found the best thing about drag, and any kind of acting work really, was the space to explore exciting new things. Your gender, your music, your identity; all of it can go hand in hand. The escapism truly saved my life at my lowest points.

I would be lying if I said it's been easy finding a balance. I even struggle now with that. But what I would say, as a singer, is take care of yourself, voice and body. And your mind – your mind needs as much self-care as your body.

You often talk about CF in your shows; what do you think is the importance of raising awareness of the condition?

We are living in the new age of modulator drugs which is exciting. However we know that some people with CF still can't benefit from the modulator drugs, so we need to keep channelling our efforts into helping those people. If I hadn't been given Kaftrio when I did, I might not be here to fill the world with joy and colourful make up. I encourage everyone to do your best in supporting the Trust and the efforts they go to in terms of research for the world of cystic fibrosis.

Thanks for your support, Jordy! If you had one bit of advice for a young person with CF today, what would it be?

I'm a big believer in always listening to your gut. In any situation, it never lies. Let yourself make mistakes, you are not perfect, perfection doesn't exist. And always remember if you feel different and you don't belong, there is space for you – sometimes you just have to find it. That takes time, energy and a boss soundtrack of sassy tunes.

Looking to the future, what are your hopes and dreams?

I've been busy putting together an EP, which I hope to release soon. I'm ready to get out there, meet people and travel. I'm writing a book about my life and all the negative experiences and failures, and how they shaped me and who I am today.

In 2023, I will be doing my last drag show, which was funded by Creative Scotland. It's called ***12 WEEKS***, and it looks at my life during lockdown and shielding. And then… who knows? As Donna Sheridan said in ***Mamma Mia 2***: "Life is short, the world is wide. I want to make some memories."

For the CF community, I dream of the day we have treatments that could repair the damage in CF.

Thanks so much for sharing your CF story with us, Jordy!

If you'd like to share your story, please get in touch at **stories@cysticfibrosis.org.uk**

#CFTruths

Caitlin

Back in the spring, we launched #CFTruths, a campaign to help increase the public's understanding of cystic fibrosis and show what everyday life with the condition is really like. The campaign was devised by Caitlin, who has cystic fibrosis and was struck by how the COVID-19 pandemic made common many of the everyday experiences of the CF community.

"The idea sparked from a conversation with my CF nurse, who called me before a hospital visit to check that I didn't have COVID-19," recalls Caitlin. "After the first question, 'Do you have a persistent cough?', there was a pause… I've known this nurse for nearly a decade, and have had a cough the whole time due to my CF. Of course! What do you think I'm coming in for? "We laughed it off, but unfortunately most people don't find my cough as amusing. Thus, 'we were coughing before it went viral' came to be."

Caitlin soon realised there were many more parallels between living in the pandemic and living with cystic fibrosis: social distancing from others with CF, fear of catching a dangerous infection, and restrictions on socialising and travelling.

"It has always been difficult to get people to understand what it is like to live with CF, but this campaign might help by relating it to our universal experience of the pandemic. Of course, both COVID-19 and CF are much more than what is captured in the snappy headlines – but when you delve deeper, we're really comparing one serious, life-limiting disease to another."

Caitlin hopes the campaign has inspired people to learn more about the burden of living with CF, and also empowered those living with CF to own conversations around their condition.

"Some people find it difficult to talk about, as it's extremely personal and I think there is sometimes a fear that you will be treated differently. However, it's important that people in your life understand how CF affects you so that they can support you when you need it, and talking about it prevents unfair judgements and misconceptions."

You can find out more about **#CFTruths**, and download resources to raise awareness, at **cysticfibrosis.org.uk/cftruths.**

Playing FootGolf for my country!

Stuart

Stuart Campbell, long-time supporter of Cystic Fibrosis Trust, is one of the world's leading footgolfers. He has travelled the world playing with the Scottish national team and hopes to compete at the World Cup in Orlando next year.

I was diagnosed with CF when I was one. Not much was known about CF in the 80s, and growing up my parents were told that I wouldn't even be able to climb the stairs, let alone take up any sports. But as I got older, I realised that I was fitter than lots of my friends and I've tried to never let CF define me.

I got into FootGolf when I went to play with some friends on a day out. I shot a decent score and got given contact details for a local team. I went along to see what it was all about - and I was soon hooked!

FootGolf is a hybrid sport, combining football and golf. It's played on golf courses with larger holes, uses a standard football and follows golf rules. It's one of the fastest growing sports in the world.

I love how competitive it is for a relatively unknown sport. I get to travel all over the world to play; meet new people and experience new cultures. This year I'm playing in Amsterdam, Paris, Geneva and Turkey. And in 2023, the Scotland National Team will head to Orlando to compete in the 2023 World Cup. We are one of the strongest squads in the world, and if I make the squad for the World Cup, it will be my greatest achievement.

Playing FootGolf helps keep my lungs as clear as possible, as it's a lot of walking and some courses are very long. FootGolf can be played by anyone, regardless of age, sex or ability. It's perfect for those with CF as it's played outdoors, so you can keep a distance to stay safe from infections. It's great for your mental health too.

If anyone in the UK is interested in playing in any events or just want to know about local courses, you can find lots of information on Facebook by searching for:

- **FootGolf Association of Scotland**
- **FootGolf Association of England**
- **FootGolf Association of Wales**
- **FootGolf Union of Ireland**

Your CF team can help advise you on the different types of exercise that might suit you.

How do you stay active with CF? We'd love to hear your stories! Get in touch at **magazine@cysticfibrosis.org.uk**.

Cystic Fibrosis Trust

Make strides to a life unlimited

Great Strides is back for 2023! Put your best foot forwards and help fund ground-breaking new treatments for everybody with cystic fibrosis.

Sign up today for our special earlybird registration fee from £30.

When: 17 June
Where: Brecon Beacons
What: 20km or 40km – you decide!
Why: Every penny raised will help bring forward the day when everybody with CF can live without limits.

Find out more at
cysticfibrosis.org.uk/greatstrides

Registered with FUNDRAISING REGULATOR

Uniting for a life unlimited

Coping with the cost of living crisis

The rising cost of living and the financial burden of living with a life-long condition is an increasing worry for many people with cystic fibrosis. In a recent survey to help us better understand the true cost of living with CF, 87% of respondents said they were worried about the cost of living, and 1 in 3 worry about money daily. While we can't solve everything, Sangeeta and Nicky from our Welfare and Rights Team have put together some top tips to help the CF community cope in these challenging times.

You can find more information and support on our website at **cysticfibrosis.org.uk/costoflivingsupport.**

1. Help with energy costs

If you need a little extra help from your energy company, including more support during a power cut, you can contact your energy supplier and ask to be added to their priority services register and ask that your details are also added to the electricity networks priority services register, these are free UK-wide services. When on the registers, your energy provider should ensure you are on the best tariff and are supported if you fall into arrears.

If you are on home oxygen, you may be able to access a rebate on your energy costs, to help with the higher energy bills an oxygen concentrator can bring. Speak to your oxygen provider for more details.

If you live in England and Wales, it's also worth checking out the WaterSure scheme, which allows certain water users to have their bills capped if someone in the home has a medical condition which requires a significant use of water.

You might also be able to get a grant from a charitable trust to help with your energy bills. Check out the Citizens Advice website for more information if you live in England, Wales or Scotland. In Northern Ireland, Advice NI outlines some of the support you may be able to access.

2. Council tax discounts

If you live in a larger home than you would need if you or another person was not disabled, check if you qualify for the Disabled Band Reduction Scheme (Disabled Person's Allowance in Northern Ireland).

If there is a room (other than a bathroom, kitchen, or toilet) which is mainly used for the treatment or care of the person with CF, or there is extra space inside the property for using a wheelchair, you can apply.

If you qualify, your bill will be reduced to the next lowest council tax band. If your home is already in the lowest band (Band A), you'll get a 17% discount on your council tax bill instead, or up to 25% discount in Northern Ireland. When you apply, you can also ask for the discount to be backdated for up to six years (so long as you are eligible during this time).

3. Reductions in council tax

You could be eligible for a reduction on your council tax if you're on a low income or claim certain benefits. Your bill could be reduced by up to 100%. You can apply if you own your home, rent, are unemployed or working.

What you get depends on your household circumstances, and where you live – each council runs its own scheme. If you live in England, Scotland, or Wales, you can use the tool on the **Gov.uk** website, and it will take you to your local council's scheme. There's a different scheme in Northern Ireland known as Rate Relief. You can read about this on the **nidirect.gov.uk** website.

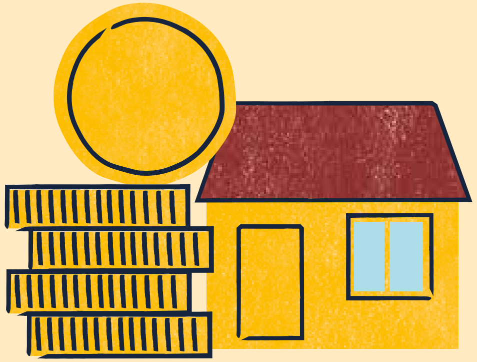
4. Help with rent

A discretionary housing payment (DHP) is an extra payment if you're struggling to pay rent and get the universal credit housing element or housing benefit. You can apply for this online via your local authority website.

5. Charitable grants

Turn 2 us is a website which allows you to search for charitable grants that do not have to be paid back. We also have a number of welfare grants available to help support people with cystic fibrosis and their families through challenging times. You can find out more on our website at **cysticfibrosis.org.uk/grants**.

Governments and local authorities have also made money available to support people in urgent financial difficulty. You'll find more info on your local authority website in England and government websites in Scotland, Wales and Northern Ireland.



Please remember, if you are struggling with money worries, there is lots of expert advice available – you may want to get a benefits check, seek some money advice and get some support with budgeting. Our Helpline or your CF social worker can point you in the right direction for this support.

Call our Helpline on **0300 373 1000** or email **helpline@cysticfibrosis.org.uk**.

On your marks, get set, go…

Mayara

On Sunday 2 October, tens of thousands of people will be limbering up for the TCS London Marathon! Among those taking part will be Mayara, Robyn, and Jennifer, three amazing runners from Team CF. With the countdown well and truly on, we caught up with the trio to find out how their training is going and their motivations for taking part.

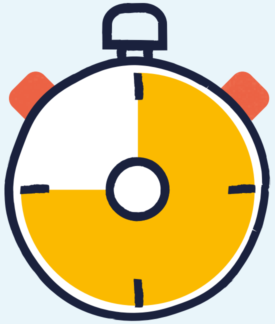
Mayara's story

Mayara is a physiotherapist and researcher working in public health. While completing her PhD at one of our Strategic Research Centres, Mayara saw the difference the Trust makes to families living with CF across the UK. "These families were always having to deal with so much, yet they always showed an incredible drive, love and unity, and that made me want to be a better version of myself," Mayara says.

"Through my work as a CF researcher, I saw first-hand how the Trust always put the interests of families first. They make sure they are listening to the CF community and translating their feedback into action."

Mayara was due to take on the London Marathon last year, but complications from COVID-19 meant she had to defer her place to 2022. With race day fast approaching, training is getting tough, Mayara admits, but she's still feeling really excited for the big day. "I'm hoping to make all the amazing people who have donated and the Trust proud on race day! In the tough moments, the amazing CF community keep me going.

"To me, making sure that everyone with CF can live a life unlimited is the main goal. The only way to achieve this is by investing in research and treatments."



Robyn

Robyn's story

When Robyn was on the waiting for list for a transplant, she promised herself two things: "That I would run a marathon if I got a transplant; and that I would raise as much money as I could for Cystic Fibrosis Trust."

In 2015, Robyn received her double lung transplant. She started running to "exercise my new lungs", and seven years later, here she is, preparing to run her first London Marathon for the Trust! "When I heard that I had got a place I was overjoyed… and also a little apprehensive," she remembers. "Even now, seven years after my transplant, I feel incredibly lucky to be here and to be so well. During a tough training run my thoughts often turn to what life was like for me before my transplant and, of course, my donor and their family."

Robyn hopes the money she raises will help bring forward the day when everyone with CF can live a life unlimited. "The Trust is such an amazing charity for the diverse work that they do to support people with CF and their families. Any amount of money raised for them will make a huge difference to the lives of thousands of people."

Jennifer's story

Jennifer started running after her son Theo's CF diagnosis – and hasn't looked back since! "It was partly for my own physical and mental health, but mainly also to set a good example for my sons," she says. "They are both now regular junior parkrunners, as well as being my most vocal supporters during races!"

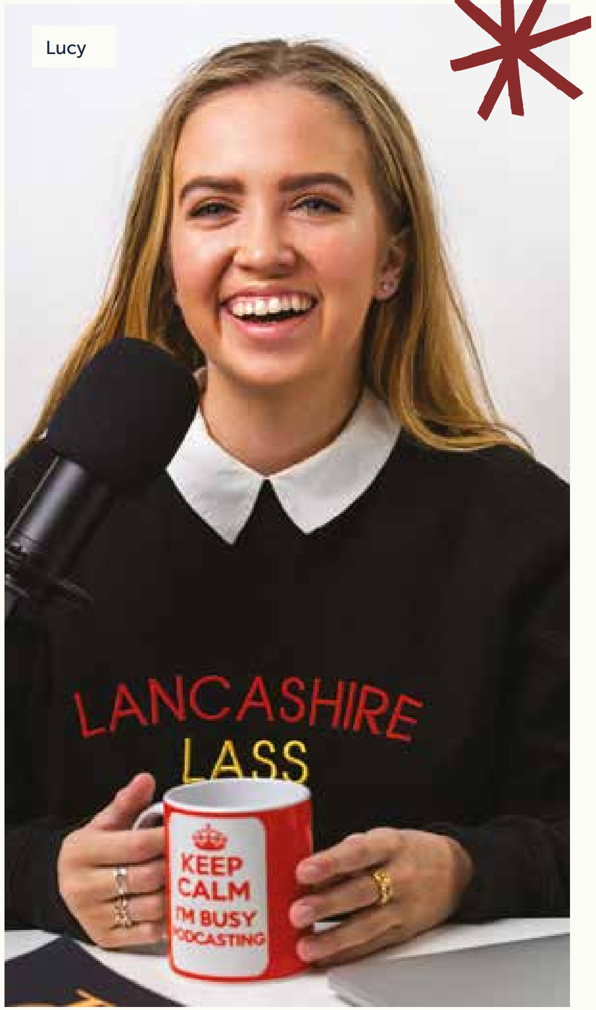
Over the years, Jennifer has found the Trust's information and support invaluable, which is one of the reasons she was inspired to fundraise. "We have felt their support via the website, via the Helpline and all of the resources available to help us as Theo progresses through each stage in life.

"We are also so hugely grateful for the life-changing drugs that Theo can now receive, and we want to make sure that progress continues."

Jennifer

We'd like to say a big thank you and good luck to all our Team CF London Marathon runners. You've got this!

We have a huge range of events throughout the year, with something to suit everyone. Whether you're a runner, gamer, baker or thrill seeker, you can find a way to challenge yourself and raise vital funds for people affected by cystic fibrosis. Find out more at **cysticfibrosis.org.uk/teamcf.**



Listen up!

Lucy Baxter is the host of the Trust's brand new podcast series, *CForYourself*, as well as hosting her own podcast, *From a Lancashire Lass*. Here, she explains more about what inspired her to start podcasting, her passion for telling stories, and following in Graham Norton's footsteps!

I'm Lucy, I'm 24 and I'm from a small village just south of Preston. I was diagnosed with cystic fibrosis when I was just over two years old.

I finished my Masters in Broadcast Journalism last September. Since then, I've been working as a freelance broadcast journalist at BBC Radio Manchester and have been on tour with the BBC to mark their centenary year by sharing my CF story in secondary schools around the North West of England.

More recently, I was offered a job as a reporter at Farmers Guardian, which is a weekly magazine with the latest news relevant to farmers in the country. My dream is to one day become a television presenter; I'd love to interview people like Graham Norton does!

This is actually why I originally set up my own podcast, ***From a Lancashire Lass***. I was in a lecture learning all about media law and I was quite shy at talking to people – which may be quite hard to believe for those who know me! I decided to focus my podcast on people from Lancashire as there was nothing like this already out there. I'm now in the middle of season two of my podcast and have released a new episode every Friday since December 2020 without fail, even when I had COVID-19.

When I was approached to host ***CForYourself***, I was delighted because it was another opportunity to improve and gain experience in presenting and interviewing – but more importantly, because I would have the chance to give a voice to people with CF. With cross infection, we can never mix, so I hope people with CF know that they aren't alone and that by listening to me chat to them, it provides an intimate experience where they feel like they are in the same room as me chatting or listening to a conversation.

> **"A podcast is such a personal and intimate form of communication"**
>
> Lucy

Podcasting is just one of my many hobbies! In my spare time, I enjoy tap dancing and going to the gym. In lockdown, between my undergraduate and postgraduate degree, I trained to become a Zumba instructor and just love teaching the classes. I love cross stitching and have recently started beekeeping.

I am lucky that I can take Kaftrio. It has really given me another zest for life. I have more energy, my lung function has gone up and I feel far less breathless. I stopped coughing and my voice has so much more clarity when I talk now. Kaftrio has meant that I can plan my future with more assurance that it will happen, like planning for my future dream career.

If there was one bit of advice I'd give a young person with CF today, it would be to know that we are such determined and resilient people. We have an incredible fire in us to keep going.

Find out more about *CForYourself* and where you can listen at **cysticfibrosis.org.uk/podcast**.

Behind the scenes

The Trust's latest animation and activity pack for children will help them, their siblings and their friends understand the condition in a fun and interactive way.

Cystic fibrosis can be hard enough for many adults to get their heads around. So when explaining CF to children, it's really important to explain it in a way that is relevant, accessible and engaging.

Having CF today is a very different experience than what it was just a few years ago. That's why we regularly review many of our information and support resources to make sure we meet the needs of our community.

Last summer, a parent reached out to the Trust, asking for more materials for young children to help them understand what CF is, reinforcing to us that there was a need for a fun, interactive way for children with CF, their friends and siblings to understand the condition. It was time for a fresh, new children's resource – but how do you meet the needs of children with CF in 2022? Create a resource **with** them!

> **"I can't wait to show all my friends at school so they can understand CF more."**
>
> Stanley, 6, who voices Jack

> **"Noah doesn't have CF, but his brother does and that's just like me in real life! I'm super excited my brother Stanley (who voices Jack) is on Kaftrio now, because it's going to make life a bit easier for him."**
>
> Jacob, 8, who voices Noah

Representation

In recent years it's become really important that media is representative of different groups of people. According to psychologists, positive representation can improve self-esteem, reduce stereotyping and provide validation and support for young people.

We wanted children to be able to see themselves in our new resources, and to show that there are lots of differences in people with CF and how they experience the condition. Our new characters have a wide range of differences in health, medications and treatments, as well as gender, age and ethnicity.

> **"I'm excited to be part of the animation because when I was younger, I remember watching Getting Nosey with Oli and Nush, and that helped me understand and explain to my friends what CF is."**
>
> Nell, 12, who voices Zaara

Siblings and friends

We also commissioned some research with siblings of children with CF and discovered that they needed more support to understand their brother or sister's condition. That's why the film features siblings Jack, a little boy with CF, and Noah, who has questions about how it will affect his brother.

The activity pack which accompanies the animation was created with siblings and friends of children with CF in mind, so they can do the activities and learn together.


Zaara

Involvement

The film was fully co-produced with children with CF, their families, and their clinicians helping us develop and review the animation and activity pack at every stage. They guided us in what was working and what we needed to change.

Our 'design your own character' competition got children from the CF community involved with creating a character that would appear in the animation. The choice was very difficult, with lots of great entries, but after much deliberation we decided to pick Phoebe's character Layla to appear. We hadn't initially planned to also choose a runner-up, but we loved Lydia's character Huffin the Puffin so much we also had to include him!


Lydia


Huffin


Stanley

> **"I love the art courses that the Trust does. It's really cool that some art I've done will be in a video like this."**
>
> Lydia, 11, who designed Huffin

> "I'm excited that the character I designed will be part of a video about CF. I think it will be helpful for children with CF and their brothers and sisters, just like it was for me."
>
> Phoebe, 10 (and a half), who designed Layla

All of the voiceovers were performed by children with CF or who have a sibling with CF – and we think you'll agree that they did an amazing job! We'd like to say a huge thank you to Nell, James, Florence, Stanley and Jacob.

Layla

Phoebe

James

If you have any questions about CF, you can also call our Helpline on 0300 373 1000, or email **helpline@cysticfibrosis.org.uk**.

You can check out the animation and download the activity pack at **cysticfibrosis.org.uk/childrensfilm**

What's on your mind?

In this brand new column, our Helpline Manager Matthew answers some of your questions about life with cystic fibrosis.

Question: I'm struggling with my mental health at the moment. I've found myself becoming more withdrawn and I've been grappling with anxiety. I've not told anyone I feel this way. How can I open up and get help with this?

Matthew's answer: The past two years, with the introduction of Kaftrio, the COVID-19 pandemic and shielding, compounded by an accelerating cost of living crisis, has taken its toll on the CF community. It can be really difficult to open up about mental health. The understanding around mental health and its importance is changing but there's still a way to go, which makes it hard to seek support.

Start small by opening up to someone. Take it one step at a time. For example, the small step you could take today might be just thinking to yourself who could you trust to open up to. This can be anyone, but the important thing is that it is someone you feel comfortable with, so that when it comes to it, you actually go through with it. You don't have to then go and do it right away, but just taking that small step will allow you to feel more comfortable about it. It can be daunting organising your thoughts and verbalising how you feel. Try and make a few notes to help you. You could even write it out to send as a message to someone over text, if talking on the phone or face-to-face feels too scary right now.

However, sometimes being too over-prepared can create anxiety in itself. If you feel this way, you may want to wait for a natural point to open up. It can simply be a case of gently saying how you feel when a friend or family member asks how you are in conversation.

Whichever way you decide to open up, it gets easier when you unburden yourself from bottling up your feelings. Remember, you can also talk to your CF specialist team who may have a psychologist or social worker within the team. If you'd like to talk to someone in confidence, our Helpline is open from 10am to 4pm, Monday to Friday on 0300 373 1000, or you can email **helpline@cysticfibrosis.org.uk**.

If you've got a question you'd like to see answered in our next issue, please email **magazine@cysticfibrosis.org.uk**. Visit **cysticfibrosis.org.uk/helpline** for more information on the support we provide.

When I grow up…

What did you want to be when you were younger? Doctor? Footballer? Vet? Fireman? Dancer? The hopes, dreams and aspirations of the CF community are as big and far-reaching as everyone else's. That's why our Youth Advisory Group (YAG) has launched a new careers project, When I grow up…, to show young people with CF the possibilities that are out there when it comes to planning a future career. Here's Yasmin, a member of YAG, to tell us more.

YAG is a group of people with CF, or close to those with CF, where we meet to discuss things we can do and create to improve the lives of young people living with CF. We try and increase the ways the Trust can offer support. We try and patch some holes and think from our own experiences what we need, what's missing, and what issues young people with CF need addressing next.

My brother has CF and I wanted to join YAG to put some of my frustrations to use. I wanted to move away from just thinking about improving the clinical side of CF, and support the other more holistic parts of life with the condition.


Yasmin and her brother Kareem

My favourite part of being in YAG is finding out more about how people living completely different lives with the same conditions cope; discovering how they live their lives and seeing the resilience we as young people possess within us. It's amazing to see when someone in the group has a new achievement, and just knowing the variety within the community is always inspiring to hear.

We recently launched our careers project, ***When I grow up…*** After COVID-19 restrictions and shielding ended, and Kaftrio was approved, this made us all think bigger: what's next for us with CF?

The careers people previously were told to shy away from – careers that take longer, careers with slow progression phases, those deemed 'too demanding' – now didn't feel so out of reach. We must question what's possible. We can be inspired by those who have already broken barriers and followed their dreams when told they couldn't or shouldn't.

A seed was planted in our minds, and during CF Week we launched a series of videos on our Youth Instagram channel **(@cftrustyouth)** to show people from the CF community doing a range of interesting and fulfilling jobs.

> **"My brother has CF and I wanted to join YAG to put some of my frustrations to use and move away from just thinking about improving the clinical side of CF"**
>
> Yasmin

We asked them questions about their work and how they balance their careers with their CF, and they gave us an insight into their daily routine.

What I hope people take away from the videos is the essence of living a life unlimited. Whatever career you want to pursue, there's someone like you who has pushed through barriers with their CF to reach somewhere they want to be. We want to inspire young people to imagine a future career or feel one step closer by knowing it's possible. We also want to provide practical tips, mentors and at the very simplest, get those with CF to think bigger for their future, and imagine more possibilities.

You can check out all the videos on our youth Instagram channel **@cftrustyouth**, or on the website at **cysticfibrosis.org.uk/YAG**.

If you have an idea for the next Young Voices or would like to share your views, get in touch at **cfyouth@cysticfibrosis.org.uk**.

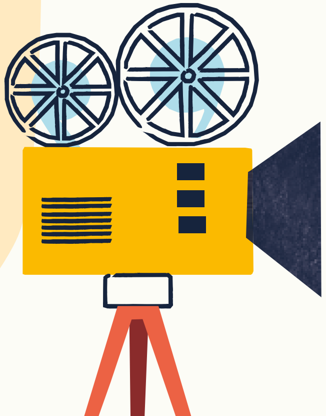
Day in the life

Paul Baverstock is an actor, best known for roles in films like *Hard and Soft* and *Close but no Cigar*, and the cult video game, *Not for Broadcast*. Paul took time out from filming to share a typical day balancing the demands of CF and life on set. Over to you, Paul!

My mornings always start with some Omega-3. Salmon and cream cheese on a crumpet is always a good choice to make sure Kaftrio has some fat to work with.

Acting preparation has a lot of vocal exercises. When in a large outdoor space like the Minack Theatre in Cornwall, an actor has to really project their voice. Some of these exercises are very similar to breathing cycles for physio.

Occasionally, I've needed IV treatment while working on set. Having a PICC (peripherally inserted central catheter) has made it easier to make CF work around my schedule.



Being flexible is extremely important as an actor because a co-star can come in any form!

I love to cook and it's important for me to set aside time to prepare a nutrient-rich dinner.

My daily routine may differ slightly from other cast members, but it's still a team effort to make the best production possible!

Find out more about Paul at **seepaul.co.uk**

If you would like to share your story, please get in touch at **magazine@cysticfibrosis.org.uk**

Cystic Fibrosis Trust

Imagine what you could change for the next generation with a gift in your Will

A gift in your Will could help us shape a better future for people with cystic fibrosis.

Whatever your gift, this special way of supporting our work will help bring forward the day when everyone can live without the limits of CF.

Find out more about how you can leave a gift in your Will to Cystic Fibrosis Trust and help more people to live the life they want for longer at **cysticfibrosis.org.uk/giftsinwills**.

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