Cystic Fibrosis Trust

Issue 12
cysticfibrosis.org.uk

CF Life

Focus
Tackling health inequalities

Feature
Shaping future CF research

Your stories
Being a carer with CF

Uniting for a life unlimited

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**

What's inside

Issue 12 – March 2022

On the cover: Shad, who features on p24
This page: Nicole and her son Arlo

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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.

All magazine correspondence should be sent to:

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Cystic Fibrosis Trust, 2nd Floor,
One Aldgate, London, EC3N 1RE

magazine@cysticfibrosis.org.uk

Welcome to CF Life

In this issue of CF Life, we look at how poverty and social deprivation can impact the CF community, and share some of the important work we're doing to level the playing field and address the health inequalities many people are facing, including our new campaign on prescription charges.

We also update you on the QuestionCF research project, which aims to find out the topics that matter most to you right now, in 2022. At a time of such profound change, we want to make sure the community and its priorities are listened to for the years ahead, so do make sure you get involved and tell us what you want to see happening in the world of CF research. And talking of research, our supporter Charlotte puts some of her burning questions to our Director of Research, Dr Lucy Allen.

Elsewhere in this edition, we hear from Shad about how he juggles managing his CF with being a carer for his mum. Poppy, a recipient of our Helen Barrett Bright Idea Award back in 2015, shares her amazing journey from receiving a double lung transplant to hosting her first solo art exhibition. Plus, we spotlight the work our Youth Advisory Group have been doing to make exercise fun for young people with CF.

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

We are delighted that Kaftrio has now been approved for use for eligible children aged 6 to 11 across the UK. This is a huge milestone in the Kaftrio journey, following years of campaigning by people with CF and their families. More than 1,500 children across the UK and Northern Ireland stand to benefit from this drug and limit the damage CF does in these critical early years. But while this is really positive news, we know that Kaftrio is not a cure, and the treatment sadly will not work for every child. We won't stop until everyone with CF has access to the support and treatments they need to live a life unlimited.

Find out more about our campaigns at **cysticfibrosis.org.uk/campaigns**

Research

CF affects everyone differently. Some of these differences can be explained by the genetic make-up of each individual. To develop life-changing treatments that work for everyone with CF, researchers need to use genetic information to help them approach the right volunteers for future research studies and clinical trials. An exciting new CF project within the National Institute for Health Research (NIHR) BioResource – Rare Diseases aims to help with exactly that by creating a register of study volunteers whose genetic information has been analysed.

Find out more about this project and how you can take part at **cysticfibrosis.org.uk/BioResource**

Care

We've been working hard these last few months on updating our information resources, including some of our physiotherapy leaflets and information on portacaths, home intravenous therapy, inhaled therapies, steroid treatment, and genetic testing. The CF community have reviewed these publications along the way to help us make sure they're easy to read and understand, and include all the information you're looking for on that topic. All of our information resources are available to download for free from our website at **cysticfibrosis.org.uk/information**, or you can order them by contacting our Helpline on 0300 373 1000 or **helpline@cysticfibrosis.org.uk**.

Fundraising

Calling all gamers! Did you know you can play the games you love AND raise vital funds to support people with cystic fibrosis? #CFNextLevel is our gaming challenge and it's really easy to get involved. Whether you're a console or PC gamer, to join in all you need to do is pick your game, choose your challenge, select a date and get gaming!

Gaming can be done online or offline, virtually or in person; the possibilities are endless. And if you prefer your gaming on a board or with cards, you could even hold a games night with friends. Why not dig out your favourite childhood games for a night of nostalgia?

Sign up today at
cysticfibrosis.org.uk/cfnextlevel

#CF NEXT LEVEL
In aid of Cystic Fibrosis Trust

Support

Back in the winter, we submitted a detailed response to the Government's Health and Disability Green Paper and made sure your voice was at the heart of it. We asked people affected by CF to tell us their experiences of disability benefits, including Personal Independence Payment (PIP). We had a huge number of survey responses and comments via social media. This meant that we were able to submit a response to the Government which strongly reflects the CF community's experiences of PIP, and we could make clear recommendations for how the benefits system could better support people with CF. Thank you so much to everybody who shared their views! Keep an eye on our social media channels to see how things progress.

If you'd like to share your experiences, please email **stories@cysticfibrosis.org.uk**

Shaping a better tomorrow

The CF community play a vital role in shaping our research, and it's really important to us that we're prioritising the topics that matter most to you. That's why we're passing you the baton. We're asking the whole community – people with CF, families, carers, professionals and researchers – to share your views and tell us what your CF research priorities are right now, in 2022.

Five years ago, the Trust was a partner in a research project to find out the top health priorities of people with cystic fibrosis (CF), as well as their families, carers and CF teams. The priorities have been used by the Trust and other funders, both nationally and internationally, to help us decide what research we fund; and by doctors and scientists to focus the direction of their studies. Much of the research inspired by this project is still ongoing and due to the nature of medical research it may take some years for the results of this work to be seen as making a real difference for people with cystic fibrosis.

The top 10 CF research priorities agreed in 2017:

1 What are the effective ways of simplifying the treatment burden of people with CF?

2 How can we relieve gastrointestinal (GI) symptoms, such as stomach pain, bloating and nausea in people with CF?

3 What is the best treatment for non-tuberculous mycobacterium (NTM) in people with CF (including when to start and what medication)?

4 Which therapies are effective in delaying or preventing progression of lung disease in early life in people with CF?

5 Is there a way of preventing CF-related diabetes (CFRD) in people with CF?

6 What effective ways of motivation, support and technologies help people with CF improve and sustain adherence to treatment?

7 Can exercise replace chest physiotherapy for people with CF?

8 Which antibiotic combinations and dosing plans should be used for CF exacerbations and should antibiotic combinations be rotated?

9 Is there a way of reducing the negative effects of antibiotics e.g. resistance risk and adverse symptoms in people with CF?

10 What is the best way of eradicating *Pseudomonas aeruginosa* in people with CF?

Time for a refresh

Just as any good traveller will check a map from time to time to make sure they are going in the right direction, at the end of last year we felt it was time to review the research priorities – so a research 'priority refresh' project was set up – or QuestionCF for short.

The aim of the project is to find out what your CF research priorities are now, in 2022.

Are they the same as they were five years ago? Would you reshuffle the top priorities in a different order? Or are there new priorities that weren't on the list before? Finding answers to these questions will help us make sure we're on track to help people with CF live a life unlimited.

"A lot has changed for people with CF in the last few years: many have access to CFTR modulators, and due to the pandemic, many people's care will have changed, such as with remote clinic appointments and remote health monitoring. The research priorities need to be current and they need to be relevant, so it is time to look at them again," said Dr Lucy Allen, the Trust's Director of Research

The project is being organised by the University of Nottingham, the Trust and people from the CF community, with support from the James Lind Alliance team at the National Institute for Health Research (NIHR). People with CF, parents, doctors, representatives from CF clinical teams, researchers and representatives of other CF charities across the world are members of the team managing and overseeing the project.

Nicole, whose son Arlo has CF, shared her experiences of taking part in the research priority refresh project steering group.

"As a CF parent I feel like there's so many things that I can't control, so it is really great to feel that you're able to do something proactive by giving your voice as a person in the community."

Nicole and son Arlo

"On the day of a steering group call, my 15-month-old son Arlo had just been admitted for his first hospital stay. It was a big shock for me and my husband. After the call I felt really refreshed and re-energized knowing that there's a much wider group of people who are working together to make things better for the CF community."

What's happened so far?

There are three stages to the project, and the first stage is already complete. In January our community were asked to complete an online questionnaire. Its purpose was to see if the top research priorities from five years ago were still relevant today. Each person was asked to pick all the existing research priorities that were important for them, and if their priority wasn't on the existing list, there was space to add new ones. This survey has now closed. Researchers at the University of Nottingham are currently sorting through all of the answers that have been received.

> **"As a CF parent I feel like there's so many things that I can't control, so it is really great to feel that you're able to do something proactive..."**
>
> Nicole

In April there will be another chance to have your say when a second survey will open. Anyone can take part and it doesn't matter if you did the first survey or not. In the second survey, you will be asked to choose your top health priorities from a list of around 50 priorities, pulled together from the responses to the first survey.

Finally, in the summer, an online workshop will be held to do a sense-check and reach consensus on the top 10 priorities that come out of the second survey. Following this, the refreshed top 10 priorities will be published in the autumn and made available for researchers, clinicians, and funders to use going forward.

"We'll use this to determine which research studies we fund and what areas we need to push for – where there's not enough research that happens at the moment," said Dr Lucy Allen.

How can I take part?
You can take part in an online survey which will open in April. A link to the survey will be posted on the research priority refresh project website, and on our social media channels.

Can people under the age of 18 take part?
Absolutely! Everyone is welcome to take part, but children may need an adult to help with the reading and typing. Every family member can take part separately if they wish.

What do you want to know?
We want to know which research priorities from a list in the survey are the most important to you. Or to put it another way, what the top research priorities are that you'd like to see researchers investigate.

Why should I bother?
We're keen to make sure that research we fund is relevant to people with CF and those that support them. Doctors and scientists can use these priorities to help design their next research studies – and the Trust and other funders will use it to ensure we fund research studies that answer your questions, and encourage other research funders to do the same.

I don't have CF, do you want to hear from me?
Yes! We're asking for people with CF, parents, family members, friends, CF teams, and university or hospital-based researchers to choose their priorities for research.

How have the original CF research priorities made a difference?

For funders and researchers alike, the 2017 list of top priorities became one of the guiding principles in deciding which areas of CF to focus on. The Trust alone has provided over £10 million of research funding to address these priorities, leveraging an additional £13 million of co-funding from other research funders.

Some of the studies inspired by the identified priorities include finding better ways to diagnose CF lung infections such as *Pseudomonas aeruginosa* and non-tuberculous mycobacterium (NTM). Reduction of treatment burden in CF – the top priority – is being tackled by two quite different research approaches. Studies such as Project Breathe are evaluating whether it is safe to change some care appointments to virtual visits and tailoring the focus of in-person clinic visits. And, following the introduction of Kaftrio, Dr Gwyneth Davies and Professor Kevin Southern are leading the CF STORM study, investigating whether mucoactive nebulisers (such as hypertonic saline or dornase alfa) can be stopped. Further examples of research studies underway can be found in our 'You said, we did' article published on our website over Christmas.

Professor Alan Smyth

"The top CF research priorities in 2017 made me completely reassess the research programme my group have been engaged in for many years. They showed the importance of gastrointestinal symptoms to people with CF and how disruptive these symptoms can be to school or work. This made me reach out to colleagues working in other areas of medical research to form new collaborations, which will answer some of these questions and to find new approaches to fix them. Hearing the patient voice has re-energised and refocussed my research," said Professor Alan Smyth, CF clinician and researcher at the University of Nottingham leading the priorities refresh project.

Find out more about the QuestionCF research project and how you can get involved at **questioncf.org**

When Charlotte met Lucy

Our Director of Research, Dr Lucy Allen, is keen to hear about your priorities for CF research in an exciting new project (see page six to find out more). We asked our supporter Charlotte, who has CF, to turn the tables and find out Lucy's priorities for research and her hopes for the future.

Charlotte

Charlotte: Do you think that your priorities as a researcher are different from the priorities of someone with CF?

Lucy: There is the potential for that difference, between the research priorities of a scientist and someone with CF. When I was working in the lab earlier in my career I'd always want to know the 'so what' of my research. For CF research there are lots of interesting puzzles to solve, but there are things to focus on that have the potential to give the CF community answers to questions that are important to them sooner.

Charlotte: My mum was told never to use the word cure. Now that we've made so much more progress, could a cure be reachable?

Lucy: We need to think about the immediate needs of people with CF as well as the long-term goals, and the long-term goal is that cure. Helping us to better understand those immediate needs is where the research priority refresh project is going to be really important. It will allow people to tell us exactly how they're feeling right now, and therefore what their research priorities are, whether they are to address immediate health needs or more longer-term priorities.

Charlotte: There seems to be a lot of research into lung infections caused by the bug non-tuberculous mycobacteria (NTM), is that because it has always been there? Or is it a new bug on the scene?

Lucy: In the US in the late 1990s, NTM started to become a more common bug within the CF community, and then in the UK you could start to see the increasing rates of infection. When we got the top 10 research priorities in 2017, treatment for NTM infections was the third priority on the list. In response, researchers are looking into the best treatment regimes to deal with NTM, funded by the Trust and internationally. It demonstrates how powerful these research priority exercises are in identifying something that's bubbling up within the CF research community.

> **"For CF research there are lots of interesting puzzles to solve, but there are things to focus on that have the potential to give the CF community answers to questions that are important to them sooner."**
>
> Dr Lucy Allen

Lucy

Charlotte: Everyone's CF is going to be so different; reactions aren't going to be the same and treatments aren't going to be the same. What do you think will happen in the long run?

Lucy: With CF there's so much happening in the body, and treatment and management needs to be on an individual level. For example, one person doesn't do the same amount of exercise as the next person, or one person may stick to their meds more than someone else. All of those questions can't be answered in one study. Researchers are asking one question at time, as they are with the CF STORM study, which aims to find out if stopping certain daily mucoactive nebulisers is safe for people taking Kaftrio. (You can find out more about CF STORM at **cfstorm.org.uk**). It's likely that there will be similar studies to this, asking questions like 'if I stop taking that, what happens?' or 'if I do more of one thing, is it better than another?'. Eventually we'll have enough evidence to develop some guidance around them.

How can I get involved in CF research? Check out our Trials Tracker to find clinical trials you can get involved with in your area. **cysticfibrosis.org.uk/trialstracker**

Being a carer with CF

For much of his life, Shad has juggled his own CF with the responsibility of being the main carer to his mum. Here, Shad writes about his CF journey, the emotional and physical challenges he faces every day, and why he's determined to make sure other carers with CF can access the support they need.

Shad

I first started showing symptoms of cystic fibrosis when I was 6 years old, but I found that doctors didn't take me very seriously. It wasn't until I was 23 that a sweat test showed I had CF.

The hardest part growing up was having no advocate for my health. From the age of 10, I helped my mother, before and after school, to look after my father when he had his first stroke. I was hands-on every day and learnt to engage with Social Services during my GCSEs and A-Levels, and to fight for support for my father, all while my CF was undiagnosed.

My father passed away shortly before I was diagnosed with CF. I had to pull out of university due to a combination of being unwell and the need to look after my mother. My care giver role never actually stopped, and in recent years the demands have accelerated, with my mother's health deteriorating. She has history of heart disease and osteoarthritis and was recently diagnosed with vascular dementia.

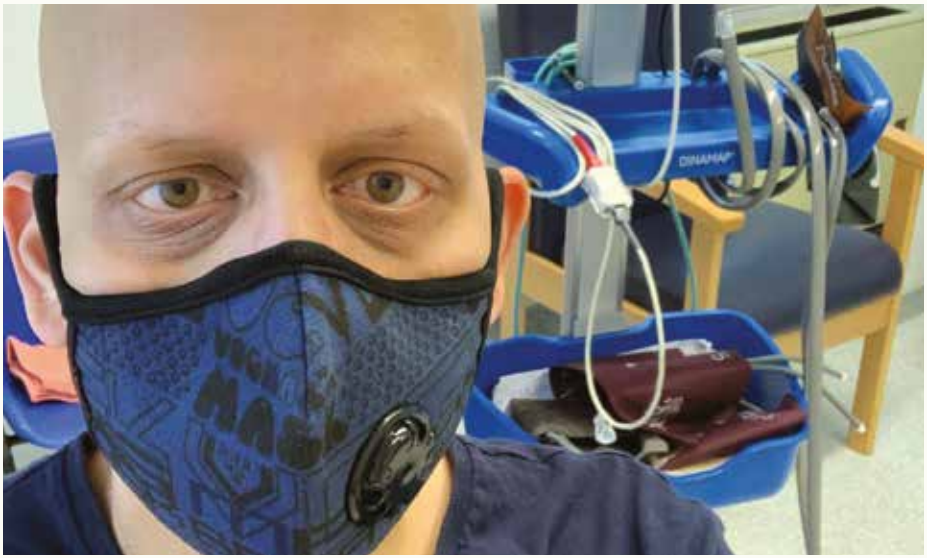
> **"Juggling these responsibilities with my own CF is challenging both physically and emotionally. I wake up so tired in the morning and I struggle to do my physiotherapy regimes."**
>
> Shad

My mother relies on me to take her to medical appointments, manage her medications and engage with her doctors. I'm also the only source of social contact for her. Juggling these responsibilities with my own CF is challenging both physically and emotionally. I wake up so tired in the morning and I struggle to do my physiotherapy regimes. Doing things socially or making time for my hobbies is really difficult too. While I have a strong sense of duty towards my mother, I haven't come across many situations like my own, where someone with CF has been the carer of their parent since childhood.

I work as a consultant for Dell Technologies and have been really lucky that they are so understanding. They make reasonable adjustments so that I can manage my CF treatments, look after my mother and still contribute to the business. I am also able to work from home which I am incredibly grateful for, as it helps with my energy levels and the tiring demands of doing daily physiotherapy.

"I am sharing my story to raise awareness and help other carers with cystic fibrosis who are in a similar situation, as I don't think there's enough support or understanding out there."

Shad



When it comes to accessing support, I have had many Carer's Assessments by my local council, but they just get filed away with no one following up. It seems like they only have defined 'tick boxes', which are not flexible enough to take into account a registered carer with a long-term condition.

I don't want others to go through what I have. I am sharing my story to raise awareness and help any carer with CF who is in a similar situation know that they're not alone. My hope is that one day, people with chronic and hidden illnesses such as CF can find the support they need. If I could offer any advice to carers, it would be to ask your CF team to write a supporting letter to Social Services, document your engagements with the council and ask your MP for help.

Engaging with Cystic Fibrosis Trust has been a blessing. Through their support, I have had the courage to speak up and share my story. The Trust has been the missing advocate for me. It is also fantastic to be a part of their Involvement group, as it gives me the opportunity for my voice to be heard on a range of topics that will shape future support for people with CF, so that we'll all able to live a life unlimited.

If you'd like to access support or information on any aspect of life with CF, you can call our Helpline on 0300 373 1000 or email helpline@cysticfibrosis.org.uk. Find out how you can connect with others in the CF community at cysticfibrosis.org.uk/support

Introducing the new CF Forum

Earlier this month, we were delighted to launch a new online forum for the CF community. It's a safe space to seek information, access support, and chat with others who know what you're going through. Here, our Helpline Manager Matthew Delooze shares an insight into what you can expect from your online community and how we've worked with people with CF to create it.

Over the past year we've worked hard together with people affected by CF to create a new online forum which is a safe space for asking questions, seeking support, or just simply connecting with others in the community.

Our forum is an important space for people affected by CF to come together, share experiences and help one another. Last year we decided to do some work to breathe new life into the forum to make sure it served the community in the best possible way. We invited members of the community to talk to us and tell us what has worked in the past and what they would like to see changed in the future. This helped us to create something that we hope will be a safe, informative, and easy-to-use resource for all.

We believe with the changes we have made you will be able to find the answer to your questions faster and connect with the community in a more user-friendly way. One key piece of feedback we received was that it must be easily accessible on all devices, and we're pleased to say the new forum works fantastically on whatever device you're using. We hope this makes using our forum more inviting and accessible for you all.

Of course, our forum is nothing without the CF community making it a vibrant, helpful and safe space, so if you have a question, you need support or just want to talk to others about CF, please join us at **cysticfibrosis.org.uk/forum.**

Exercise? It's as easy as ABC!

Staying active is a great way to take care of your physical and mental health, and many people with CF are encouraged to make exercise a regular part of their routine. But finding fun ways to keep fit and healthy can sometimes be a challenge. This is why young people in our Youth Advisory Group (YAG) developed AlphabExercise, an ABC of fun, silly ways to get your bodies moving at your own pace. From animal yoga to the umbrella dance, why not get the whole family involved and put the excitement back into your exercise routine?

Find more fun exercises on our **@CFtrustyouth** instagram.

Always talk to your CF team to discuss 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**.

Turn to page 32 to hear from two of the young people behind AlphabExercise.

A is for animal yoga. Forget downward dog, what other animal yoga poses can you discover?

O is for octopus impression. Eight legs are better than two, right?

B is for banana weights - just try not to eat them!

Images taken from AlphabExercises

Great North Run

11 September, 2022

£35 entry

Join Team CF at the UK's favourite half marathon!

Starting and finishing in Newcastle, take in the sights of Tyne Bridge with the Red Arrows roaring overhead and supporters lining the route, cheering you on!

So what are you waiting for? Lace up your trainers and help make sure everyone with CF can live without limits.

"We all had an amazing time up in the North East and it was great to run the Great North Run for a charity which is very close to my heart. Everyone had a blast and we would do it all over again in a heartbeat."

Chris Lewis, who completed the Great North Run in 2018 for Cystic Fibrosis Trust

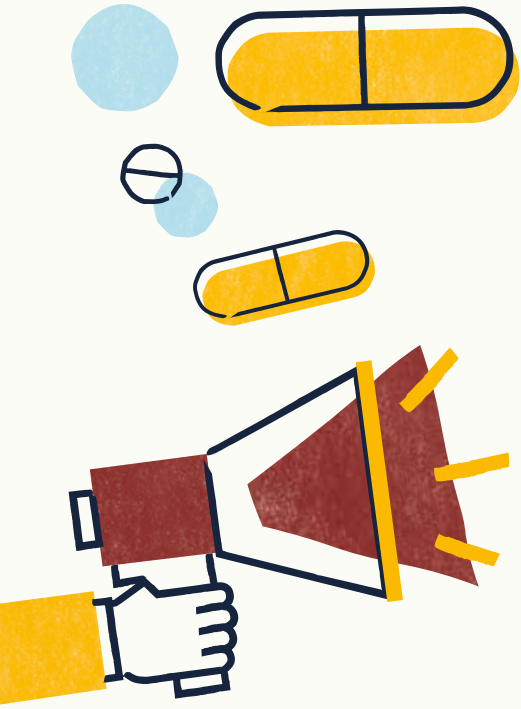
Find out more at
cysticfibrosis.org.uk/greatnorthrun

Registered with FUNDRAISING REGULATOR

Uniting for a life unlimited

Campaigning for free prescriptions

Living with cystic fibrosis often requires a huge burden of daily medication essential to stay well. But shockingly around 2,500 adults with CF in England do not qualify for free prescriptions. Find out about our new campaign to change this – and hear from Jade, who has CF, about the impact of these 'outdated' exemption rules.



CF is one of the few life-threatening, chronic conditions where people are still required to pay for prescriptions, incurring a lifelong financial burden.

When the exemption list was produced in 1968, children with CF weren't expected to live to be adults – so CF wasn't included. In 2022, there are now more adults than children living with the condition. The list is outdated and unfair, with a recent survey by the Trust showing that 95% agreed that prescriptions should be free for people with CF.

Under the current system, many people with CF will continue to incur an ongoing cost for their daily treatments through prescription charges, or will have to pay the £108 annual pre-payment certificate. One person with CF described the charges as "essentially paying to stay alive."

We believe it is vital that everyone with CF should have access to free prescriptions, regardless of where they live in the UK. We're campaigning hard on this issue, and in February a debate in Parliament called on the Government to review the prescription charge exemption list and to include everyone with CF. It is vital to raise awareness of the lifelong financial challenges faced by people with long-term conditions like CF.

How can I get involved?
For more information about the campaign and how you can get involved, get in touch with us at **publicaffairsteam @cysticfibrosis.org.uk**.

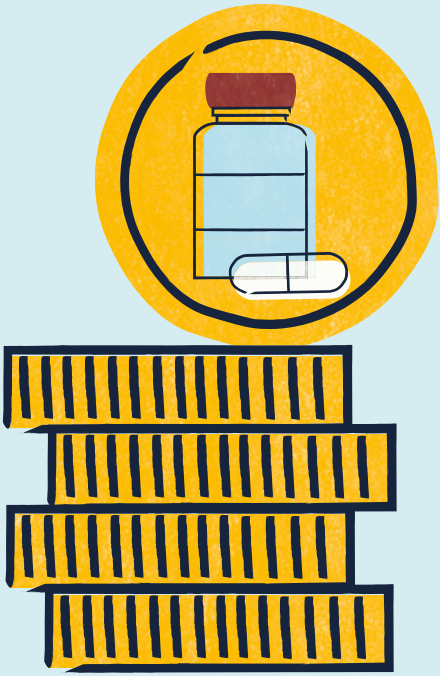
Jade's story

The year I turned 19, I was in my first year at university. I had just about found my feet, managing my complex and exhausting chronic health condition independently for the first time in my life, while also studying full-time. The day my friendly campus pharmacist told me that he would have to start charging me for my prescriptions, his voice quiet and his eyes unable to meet mine, it felt like I was being punished with yet another hurdle. I had forgotten about this archaic rule, being so focused on trying to simply live my life and stay well. That day, I left without my essential medications and I went home in tears.

Jade

"Let's make sure that no one with CF has to leave a pharmacy in tears again."

Jade



Everywhere I go, people are shocked and incredulous that I have to pay for my prescriptions. Friends, strangers, even healthcare providers – everyone can see the injustice. The cost of an annual £108.10 pre-payment certificate feels like a kick in the teeth, like I'm paying to stay alive; a reminder that I am a burden, though I never chose to have this condition.

It's only right that the outdated exemption rules are reconsidered, to acknowledge that people with CF are now living into their 40s, 50s and beyond.

I urge the Government to review the prescription exemption in England and ask that free prescriptions are made available to those with CF, so that no other young person living with this condition has to leave a pharmacy in tears again.

Make a difference on your special day

Fundraising for Cystic Fibrosis Trust takes many forms – from starting a JustGiving page for your sponsored run, to holding an auction at a sparkly ball – and now it's even easier to raise vital funds for our charity, with just a couple of simple clicks.

In 2017, Facebook launched its Birthday Fundraising feature, enabling users to collect donations from friends in honour of their big day. This feature allows loved ones to celebrate these special occasions with you, even when you can't be together, which for the last couple of years has been the case for many of us.

In the first year of the COVID-19 pandemic, we received an incredible £173,000 from Birthday Fundraising on Facebook alone. Two of our wonderful fundraisers, Erica and Adam, have shared their experience with us:

"I decided I wanted to mark my 30th birthday in a way I would remember and to celebrate the importance of this milestone with a fundraiser! I was so delighted to have over 40 friends and family donate to the Trust!

Erica

Adam and family

I've never felt ealthier and appier, and hat's down to the emarkable benefits f the Trust and their ampaigning..."

ca

"I've never felt healthier and happier, and that's down to the remarkable benefits of the Trust and their campaigning and focus over the years for all those affected by CF. I wanted to take the opportunity to raise awareness of CF and support a charity that means so much to me. Using the Facebook fundraising tool was really simple and allowed me to promote my campaign to all of my hundreds of friends and contacts!"

Erica raised £719.88 via her Birthday Fundraiser on Facebook. Thank you, Erica!

"I chose to fundraise on Facebook to raise awareness of CF amongst my friends and family. It was the perfect way of raising money while I was restricted in what I could do, with my daughter Grace being in hospital. I have chosen the Trust as Grace has CF and the Trust are doing all they can to raise awareness and funds to find a cure."

Adam raised £808.52 via his Birthday Fundraiser on Facebook. Thank you, Adam!

This simple and easy way of collecting donations and making a difference to all those affected by cystic fibrosis is why we'd love for you to join Erica and Adam in celebrating your birthday with us. To find out more about how you can support the Trust on your birthday, visit **cysticfibrosis.org.uk/birthdayfundraising**

From the art

Poppy, 31, from Wales, was a winner of our Helen Barrett Bright Idea Award back in 2015. Following her first solo art exhibition, Poppy tells her story of living with CF and receiving a double lung transplant, how it's inspired her artwork, and why budding artists should "stop scrolling and start experimenting".

Poppy

My childhood with cystic fibrosis (CF) seemed very normal and active. It was only when I went to university that my health declined and I was listed for a double lung transplant the summer that my Fashion Design degree ended. I waited three and a half years for my call and it completely changed my life. Physically, my transplant has given me much more freedom that I'm so very grateful to my donor for. However, the psychological impact of adjusting from being very unwell to suddenly well was very difficult for me, and I used art to help me recover from post-traumatic stress disorder (PTSD).

I applied for the Helen Barrett Bright Idea Award a few months after my transplant, and when I got the call to say I'd won I was truly elated. I decided it was a sign to start my career as an artist with my newly gifted health. I purchased a large easel, a digital camera, four extra-large canvases, and a heap of acrylic paint! I hid myself away for three years obsessively painting, drawing, and practicing phototherapy – a process used to deal with the darker side of living with a chronic illness.

"Living with CF and receiving a transplant is a unique experience and there are many emotions that can be difficult for others to understand."

Poppy

Living with CF and receiving a transplant is a unique experience and there are many emotions that can be difficult for others to understand. I believe we need to release them subconsciously and that's what art does for me. I don't know what I have created until I look back at it, but everything I create is a coping mechanism for these unique emotions from living with CF.

I felt very ashamed of a lot of my work in the beginning; everybody kept saying to me, "Why don't you make nice art that people want to hang on their walls?" I felt like people would judge me and tell me to "get over it", but I really couldn't stop. Then COVID-19 happened and I isolated alone for many months, making more and more art with this wild determination that I would do an exhibition one day.

In May 2021 I turned 31, had all my vaccines and began planning my exhibition ACHIMERA in the hope that I'd be able to pull it off – and I did! The best thing for me was watching people's attention change from looking at their phone or chatting with a friend, to suddenly becoming silent and really focusing in on my drawings and photographs. People came to thank me at the end and that was the most important moment for me; after all these years of doubt, I knew I'd done the right thing by staying true to myself in my art.

To any budding artists out there I would say, stop scrolling and start experimenting. You will fail so many times but with experience is confidence gained.

You can follow Poppy on Instagram **@poppyrobertsart**. Find out more about the Helen Barrett Bright Idea Awards at **cysticfibrosis.org.uk/brightideas**.

Tackling health inequalities

The cost of living with cystic fibrosis (CF) can often feel overwhelming, with the COVID-19 pandemic only adding to the financial uncertainty and hardship many in the community are facing. Research shows that poverty and social deprivation can significantly impact the physical and mental health of people with long-term health conditions like CF. Here, we delve into the data to explore this in more detail and discuss what the Trust is doing to tackle health inequality.

Let's begin by defining what we mean when we talk about poverty and social deprivation. **Poverty** relates to a lack of money to afford what most of us would think of as the basics we need. According to research by the Child Poverty Action Group, one in five people in the UK live in households below the poverty line. For people with cystic fibrosis, this could mean being unable to afford to eat well or to keep your home warm and dry – things which we know are really important in keeping well with CF.

Social deprivation is defined as a lack of resources of all kinds, and includes things like education, income and living environment. Again, for people with CF, all these types of deprivation can have a big impact on overall health.

The statistics on poverty and social deprivation are a sobering read, shining a stark light on the inequalities in our society. According to the Poverty in the UK report by Borgen magazine, since 2010, food bank usage has increased dramatically across the country; almost three-quarters of children who live in poverty live in a household where someone is working, and another 700,000 people in the UK have been pushed below the poverty line by the COVID-19 pandemic.

We have seen this increase in hardship reflected in demand for our support services. Since 2015, demand for our emergency grants has increased by over 200%. In 2016, we set up a welfare advice service which provides dedicated benefits advice to people with CF, and we have since supported over 1,000 people with Personal Independence Payment (PIP) claims alone.

The UK CF Registry has identified that over 2,000 people with CF live in the 20% of postcode areas with the highest levels of social deprivation. While we don't have data on household poverty for the CF community, we do know that half of the people who live in poverty in the UK have a disability or live with someone who has a disability.

The UK CF Registry has identified that **over 2,000** people with CF live in the 20% of postcode areas with the highest levels of social deprivation.

Some important work by researchers at the University of Liverpool has revealed that social deprivation links to worse health for people with CF. This 2013 study reported:

"Children with cystic fibrosis from the most disadvantaged areas in the UK have lower weight, height, and BMI in the first years of life after diagnosis, are more likely to have chronic *P. aeruginosa* infection, and have a lower %FEV[1]* than children in the least disadvantaged areas. These social inequalities persist into adulthood but do not widen."

(*Forced expiratory volume in 1 second, a method of measuring lung function)

Given the importance of a nutritious diet for people with cystic fibrosis, **food insecurity** is another area of concern, and this was again highlighted during the pandemic. Many families and people with CF shop carefully and have tight household budgets – shielding interrupted this and many just could not afford the costs of food deliveries or to buy the food they needed to stay well.

An article in the Lancet medical journal in 2020 reported:

"The effect of food insecurity on outcomes in children with asthma and cystic fibrosis, and other respiratory illnesses, are likely to persist for decades."

Digital poverty can also affect people with CF – for example, not having a phone or device to access health apps or have virtual consultations with your CF team. **Appliance poverty** is a key issue too – we regularly receive grant applications from people who can't keep medication cool as they don't have a working fridge, or who are washing clothes by hand because their washing machine is broken.

Ethnicity is important to consider, as people from Black, Asian and Minority Ethnic backgrounds are statistically more likely to live in socially deprived areas, according to data from the Office of National Statistics. If you take into account other research that suggests people with CF from Asian backgrounds in the UK also have worse health outcomes than White people with CF, it suggests some people with CF from Minority Ethnic backgrounds are at a double disadvantage. It's important that we are all aware of these health inequalities so that we can work together for positive change – something the Trust is firmly committed to.

Through our grants programme, every week we're contacted by people who are struggling to afford basic daily essentials. Usually, this is because something unexpected has happened – such as a hospital admission, a benefits reassessment, or a drop in employment income. In April to June last year, 52% of our emergency grants were used to cover the sort of things that many of us take for granted, like keeping our home warm or putting food on the table.

John*, who is in his early 20s and has CF, was homeless following a family breakdown, and having spent a weekend sleeping in his car, was temporarily staying with friends. He also had an issue with his benefits, and while he was trying to sort all of this out, he had run out of money and couldn't afford food or basic hygiene products. He needed a same-day urgent grant from us to ensure he could meet his basic needs.

As the cost of living increases, especially after the recent energy price rises and the removal of the £20 per week Universal Credit uplift, more and more families are stretched financially. In a recent survey, we were concerned – but sadly not surprised – to find that people with CF rely on their disability benefits for the very basics they need.

In April to June last year, **52%** of our emergency grants were used to cover basic costs.

Annie* is a toddler who has CF and requires a specific diet to keep her well. Her family are on a low income with no money to spare each month, and through no fault of their own, an error with their benefits had left them without enough money for food. Without an emergency grant from us, they would have had to manage with empty shelves and only enough money for very basic food which wouldn't meet Annie's needs.

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You're not alone

It can be hard to ask for help, and often people tell us they feel a sense of shame in dealing with CF and poverty. But you're not alone. Through the UK CF Registry and the services we provide, we know that financial worries are something that affects many people with CF, and that not having enough money for day-to-day essentials can cause physical and mental health problems for the CF community.

All of the major challenges in life that can leave people worse off can affect people with CF – unforeseen events like bereavement, family breakdown, homelessness or domestic abuse. The key issue is that for people with CF, being in financial crisis can also have a significant impact on their long-term health.

Imani* is a young woman with CF who contacted us in 2020 when, due to an error by her bank, she was left with no access to her bank account at all, and therefore couldn't access her benefits income. She had been advised to shield, meaning she was unable to get to the shops for essentials, and needed a same-day grant paid into a new bank account to ensure she could place an online grocery order.

Our grants ensure people with CF can cope financially through difficult times and in the longer-term too. While there are state benefits which aim to support people with the extra costs of living with a condition like cystic fibrosis, we know that finding your way through the benefits system can be hard.

We can check benefits and help with claims, providing support on filling in forms or helping prepare for a tribunal. We also have an income maximisation service which supports people with CF to look at any possible extra savings they could make or financial support they could access. On average, our income maximisation service has found around £4,000 of additional money per household, per year, which is really important for people on low incomes and can make a big difference.

Last year, our Welfare and Rights Advisor helped secure £1.6million of income for people with CF through expert benefits advice, and our income maximisation service has helped over 100 people since its launch in 2020.

In the past few months, for the first time ever, we have launched a Winter Hardship Support Fund. After almost two years of the COVID-19 pandemic and with the cost of living rising, the Fund, which provides a grant and ongoing support from our Welfare Team, is designed to make sure those with low incomes can afford the basics to stay well.

All of our services can be reached through our confidential Helpline by phone, email or social media, and our team will never judge anyone who comes to us for help. We also work closely with NHS CF teams, particularly the network of specialist cystic fibrosis social workers who are on the ground supporting their patients.

If you are looking for support or information on any of the issues raised in this article, we are here to help. Call our Helpline on 0300 373 1000, or send an email to **helpline@cysticfibrosis.org.uk**

As well as the services we provide, we need the Government and policy makers to better understand cystic fibrosis, provide effective support, and remove barriers to education and employment. We recently responded to a key Government consultation on health and disability, with over 450 of you taking part in the survey which shaped our response. We provided some clear requests ahead of the Government's 2021 spending review based on the issues you told us matter to you, which included an end to PIP reassessments and the removal of prescription charges for people with CF. These would be small steps to remove some of the financial pressures facing the CF community.

Throughout 2022, we will be continuing to look at the cost of living with cystic fibrosis and the effect of poverty and social deprivation on the CF community. We will work together with the CF community, specialist teams, our funders, and public bodies to level the playing field and ensure that poverty and social deprivation don't damage the health of people with CF.

*all names have been changed

Putting the fun into exercise

In Autumn 2021, our Youth Advisory Group (YAG) released their AlphabExercise project on our youth Instagram channel, @CFtrustyouth. We caught up with two of our YAG members, Cicely and Amy, to talk about the inspiration behind the project.

So, tell us about AlphabExercise!

Cicely: We thought of silly exercises for every letter of the alphabet and it was just a fun way to get people motivated. It can get boring doing the same activities day after day, so it was just a fun, light-hearted thing to do when people had been stuck at home during lockdown and maybe feeling a bit low.

Amy: It was to encourage children to do exercise without labelling it as that. It's not exercise, it's not physio, it's pretending to be Godzilla or an X-Man or just making a big mess!

Why do you think it is important to make exercise fun for young people with CF?

Cicely: We all have to do our treatments, airway clearance and take tablets... those things are so mundane. Exercise is so important for us, but sometimes when you're going through the motions it is just not fun. Even though exercise is part of your treatment, it shouldn't be viewed as that! People without CF enjoy exercise so why shouldn't we have fun with it too?

Cicely

Amy: It has always been ingrained in my head that exercise is really important and that we have to be really serious about it... that used to really put me off! My mum had the idea to do some interactive stuff with me and that took my mind off the fact that exercise was a chore or part of my treatment... then I just did it because it was really fun!

> **"Even though exercise is part of your treatment, it shouldn't be viewed like that"**
> Cicely

Images taken from AlphabExercises

Amy

What's one tip you would give to parents for making exercise fun for young people with CF?

Cicely: Go with what your child wants to do – if they find a passion in something, then let them pursue it! Forcing people to exercise in ways they don't enjoy isn't going to be productive. If your child likes a certain sport or activity, then let them go for it!

Amy: Make it into a family thing so it isn't just the child with CF who has to do it on their own. You can do interactive games, get everyone involved and enjoy it together!

What would you say to someone who was considering joining YAG?

Cicely: Do it! We're a really friendly bunch! We all either have CF or have some personal connection to CF, so we all understand what each other is going through. I was really anxious when I started, but it is such a nice group of people and there is no pressure to say anything or to be a certain way.

Amy: Just join and see how you feel! It has made me think about how I can help people who are younger than me to get the best out of life – can my experience help them in some way? It's also great to speak to other people with CF about what they are doing and hear their perspectives and opinions too.

If you are interested in finding out more about YAG, then check out our 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 on social media **@CFtrustyouth** or email **cfyouth@cysticfibrosis.org.uk**. We'd love to hear from you!

Day in the life

Our amazing supporter Pamela is mum to three-year-old Max, who has cystic fibrosis. Pamela shares their daily CF routine, featuring morning meds, beach walks and The Gruffalo! Over to you, Pamela!

1 Mornings are very chaotic in our household, as there's oral medicines, inhalers, percussion physio and a nebuliser treatment to get through.

2 Breakfast is a key time to get as much healthy fat goodness into Max as possible.

3 Max loves getting the train to nursery with his Gaga. She makes sure he runs up and down the station stairs to get the extra physio in.

4 We try and get Max outside in the fresh air every day, so he can explore and also get moving.

5 Our evening routine mirrors the morning, but with a second nebuliser treatment after dinner.

6 Our incredible Mighty Max is a true superhero and never lets CF stand in his way.

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

Cystic Fibrosis Trust

CF Week 2022 is coming!

13–19 June

Save the date for our annual awareness and fundraising week.

Wear Yellow Day 2022, our brightest fundraising day of the year!

Our annual Wear Yellow Day is back for 2022 and will take place on Friday 17 June! Make sure to save the date and share with family, friends and colleagues. It is never too early to start planning your yellow-themed event. There are so many ways you can fundraise with us again, either in-person or virtually. So whether you dress, bake, dance, walk or bounce yellow, together we can raise vital funds to make sure everyone with CF can live without limits.

Visit cysticfibrosis.org.uk/yellow

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