

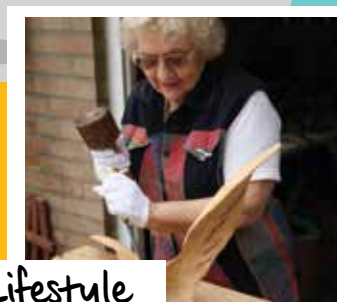


Focus

**Working nine to five?**

Coughy Break

**The accidental vlogger**



Lifestyle

**Celia carving out a future**

Fighting for a  
**Life Unlimited**

# Cystic Fibrosis Trust

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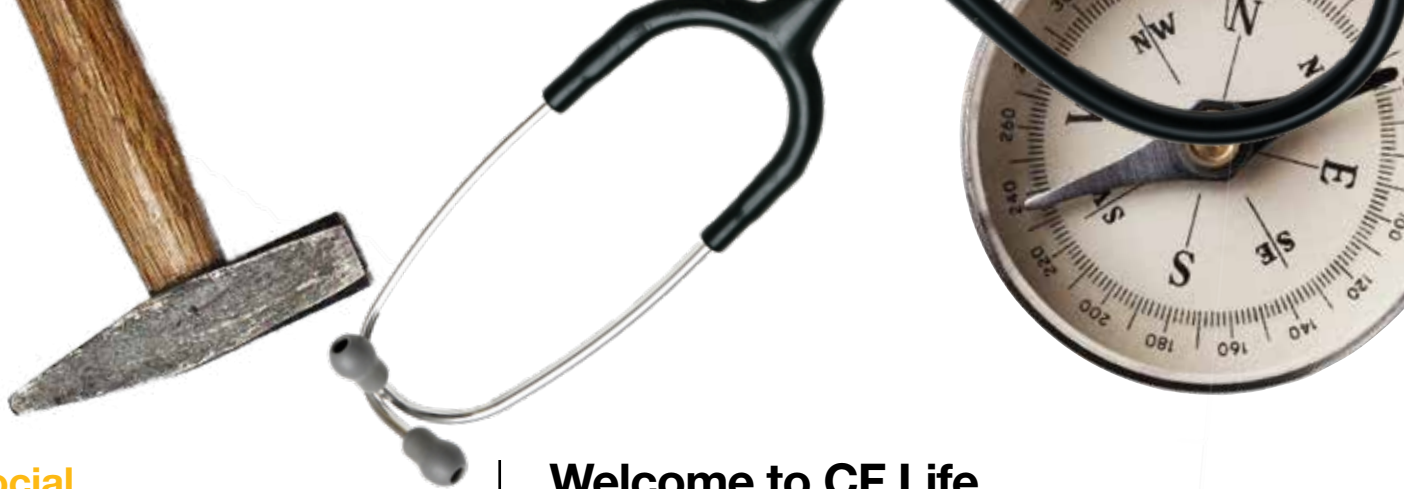
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[cysticfibrosis.org.uk](http://cysticfibrosis.org.uk)






ISSN 2513-8391

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## Social

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-  [cysticfibrosis.org.uk/forum](http://cysticfibrosis.org.uk/forum)
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## Useful contacts

### Donations

T: 020 3795 2177

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

### Events and fundraising enquiries

T: 020 3795 2176

E: [events@cysticfibrosis.org.uk](mailto:events@cysticfibrosis.org.uk)

### Cystic Fibrosis Trust helpline

T: 0300 373 1000

E: [helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk)

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

**All magazine correspondence should be sent to:**

**CF Life Editorial Team,  
Cystic Fibrosis Trust, 2nd Floor,  
One Aldgate, London, EC3N 1RE**

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

**Your feedback is  
valuable. We'd  
love to hear your  
comments.**



## Welcome to CF Life

In previous editions, we've tried to follow a particular theme, from 10th anniversaries to individualised care. But when we sat down this time to discuss the issues people were talking about, and what's happening in the world of CF, we realised there's just too much going on!

Our main feature on page 6 explores the complex balancing act of a working life and cystic fibrosis. From struggling with your lung function to educating your colleagues, you told us there are many ways CF can impact your working life – and vice versa. For some it's a simple management exercise, others have had to change their career plans, or even give up work altogether. Everyone has a unique journey.

Talking of experience, no one knows more about the ups and downs of CF than you in the community. Cystic fibrosis can be isolating for individuals and families, and that's why we set up CF Connect, a pilot service where parents can support each other. On page 22 you'll hear from the volunteers working on the service and those who have found the support they needed.

Elsewhere in this issue, you'll meet Óran, the climbing canine, get up close and personal with the bugs we're out to beat, and gain some unique insights into research, social work and the magic of working mums.

Let us know what you think, and send any suggestions for future issues, by emailing [magazine@cysticfibrosis.org.uk](mailto:magazine@cysticfibrosis.org.uk).

The CF Life Team

# CF is an invisible condition – don't become invisible too!

The CF community is the heart of the Cystic Fibrosis Trust. Together, we lobbied for newborn screening for CF to be compulsory. You helped make Kalydeco available across the UK. You supported the researchers who are fighting the deadly bacteria that claim lives. But you could miss out on building a better tomorrow unless you tell us how we can contact you today.

From May this year new legislation called General Data Protection Regulation (GDPR) will mean you need to tell us if it's OK to email you, even if you told us you wanted to hear from us in the past. How you want to hear from us is up to you – by email, post, phone or SMS, this is your chance to let us know. But without your permission, we may not be able to call on you when we need you the most.



## In the last three years

thousands of supporters have got involved in our fight for access to medicines, and the battle continues.

We will keep lobbying the government, pharmaceutical companies and NHS decision makers - but we need to be able to call on you when the time is right. Without your permission, your voice may not be heard.



## Over £23,000



raised from our New Year's Resolutions email last year could support 1,000 people when they need it, through our helpline.







# Your knowledge is our strength

Whether sharing your story in our information packs, supporting one another through CF Connect (page 22) or using your insight to shape our work, you may just be an email away from changing a life.

## Over 1,000

of you visited our website from our Christmas email to give the gift of time at Christmas.



## You are driving research 1,000 people

taking part in events through a campaign could raise £450k for life-saving research.

That could be the team exploring the crippling burden of joint pain. With the extra investment your money can raise, that could become an incredible £1.8m, more than everything we've spent on the two gut SRCs!



**Giving your permission will just take a moment, but it could change a generation.**

### What do I need to consent to?

We need your permission to email you with news, fundraising and opportunities to get involved in our work.

### How do I do it?

Simply fill out the permission form enclosed with this magazine, or go online to [preferences.cysticfibrosis.org.uk](https://preferences.cysticfibrosis.org.uk).

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### Does it really matter?

Yes! From pounding pavements to petitioning Parliament, sharing stories to fundraising feats, you are the difference we make.

# Working nine to five?

Fitting cystic fibrosis (CF) around a busy schedule is a challenge, and having a condition that requires hours of treatments can mean that working nine to five (or whatever hours you choose!) can take some compromising. We spoke to four people with the condition about their experiences in employment, and while some were able to turn setbacks into new opportunities, others faced discrimination and difficulties along the way.

Read on to hear from Laura, Michelle, Natalie and Rob about their experiences, and to find out some things you might need to consider when applying for a job if you have cystic fibrosis.



For some of the people we spoke with, encountering ignorance was a sad but unavoidable truth of working with an invisible condition like cystic fibrosis.

Laura enjoyed her first job in a DIY store, but faced a negative attitude from her manager. She said: "I enjoy work. It makes me feel normal and like I am no different from anyone else. But that job took a huge toll on my health – I was losing weight, constantly getting chest infections and having time off. My manager threatened to sack me, saying that I was using my condition as an excuse."

Cystic fibrosis is considered a disability under the Equality Act 2010, meaning that employers can face serious penalties if they are found to be discriminating against someone with the condition and should provide 'reasonable adjustments' to enable their employees to do their jobs. We know that people can be apprehensive about speaking out about discrimination in the workplace – for advice and support, you can contact our helpline using the information at the end of this article.

## What is the Equality Act 2010?

A law that gives you protection from discrimination at every stage of the employment process and in wider society. This protection covers certain 'protected characteristics,' one of which is disability.



*"I have a four-year-old daughter, and keeping her safe and happy every day throws a hand grenade through any of my attempts to keep a routine."* – Michelle

*"I enjoy work. It makes me feel normal and like I am no different from anyone else."* – Laura

When Michelle struggled to manage her condition alongside her work at a law firm, her manager tried to make reasonable adjustments by allowing her to work from home every Wednesday. However, the arrangement didn't work: "I felt like an exception to their way of working, and I lasted at the company just over a year. Anyone with a condition like CF will know that you can only really flourish at work when you feel genuinely accepted by your employers."

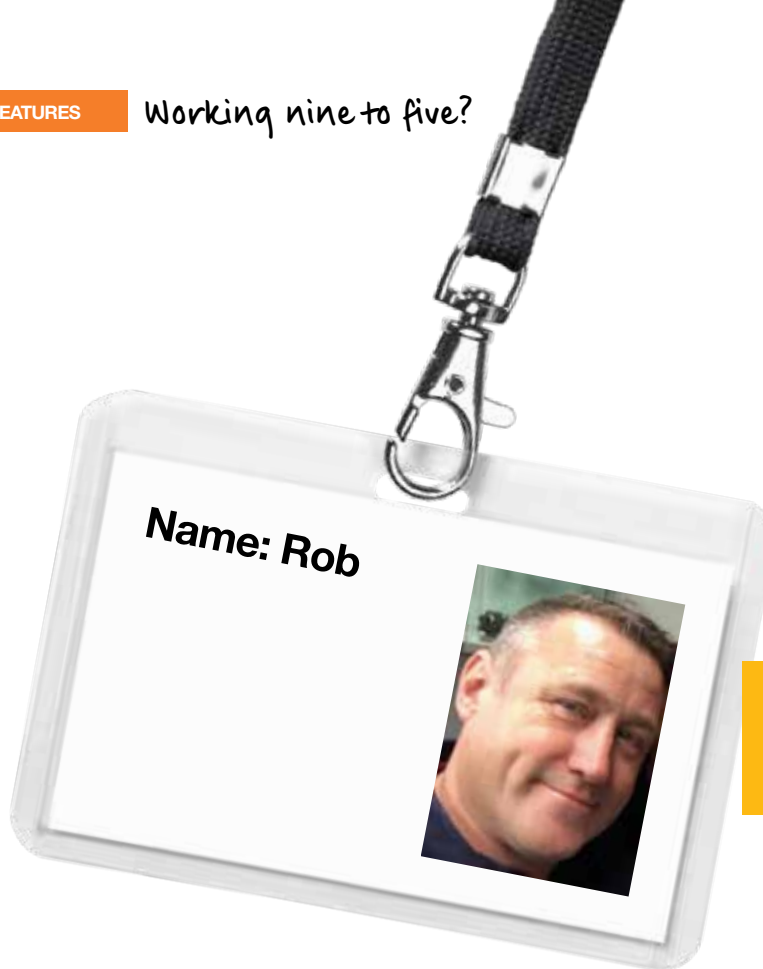
#### **Top tip:**

Check if anything in your new job might pose a risk to your health. Is there anything your new employer could do to make your working environment more suited to your needs?

Some jobs might tick all the right boxes, but have elements that pose a risk to your health. Laura left her job at the DIY store, and found an agency job at a local council, but after starting the job found that it would involve being on her feet all day.

She said: "The days were too long for me to fit in all my treatments. I fell ill for a couple of weeks, and my manager called a meeting to discuss reasonable adjustments. I suggested that leaving work earlier might help me to fit in all my treatments. My manager refused, saying instead that I could quit my job at any time."





*"They were very understanding, and after a tough couple of years and lots of admissions, I had my condition under control."*

– Rob

Laura has now moved on to a different job at the same company, with less hours and better pay, that isn't as physical, something she hopes will make her treatments easier to manage.

Natalie had to take a sidestep in her career to prioritise her health when she realised that long hours and late nights at a marketing agency were impacting the treatment and workout schedules that kept her well. She said: "While I was proud of the amazing work my team achieved, I began to realise it was at the sacrifice of my long-term health."

"My lung function had consistently remained above 100%, but after months of stress and cutting corners with my healthy habits, I wasn't feeling confident about my next clinic appointment and lung function tests. On my first attempt I hardly cleared 80%, and I decided that if I didn't hit 90% that day, I'd quit my job. Last attempt. 89%. I kept that promise to myself and I haven't looked back since."

#### **Top tip:**

**Find out if your new job has a health insurance plan that you might be covered by.**

In the past, Rob had a job that involved travelling, long hours and hotel stays, and the chaotic lifestyle hugely impacted his health. Thankfully, his employer helped him to find an office-based job close to home.

He said: "They were very understanding, and after a tough couple of years and lots of admissions, I had my condition under control." Rob returned to a job with travelling and long hours, and like many with CF was facing the dilemma of whether to change his career for the sake of his health.

"While my employer was understanding of me taking time off and allowed me to work from home, my CF team started to talk about me cutting down my hours or stopping work altogether so that I could better manage my condition. I knew I had a big decision to make."

Since then, Rob has retired from work and is starting the transplant process.

#### **Top tip:**

**Ask if your new employer is a member of the Business Disability Forum or the Disability Confident scheme. Do they have a disability policy in place?**

Natalie and Michelle have both found ways to fit their conditions around their very different passions.





*"With a flexible lifestyle working from home, I'm determined to push my lung function back over 100%."*

– Natalie

After a few weeks away from her job, which she spent exercising and completing all her treatments, Natalie's lung function was back up to over 90%. By leaving her job she has been able to continue her career and maintain her health.

"I'm now a qualified personal trainer, freelance marketer and Chief Marketing Officer at Pactster (see page 28). With a flexible lifestyle working from home, I'm determined to push my lung function back over 100%."

Michelle went on to start her own law firm, and has understanding colleagues and caring secretaries who help her to make her health a priority.

"If I am out of breath, they carry my bags. If I am absorbed in my work, they remind me to eat. Work-life balance is still a struggle - I also have a four-year-old daughter, and keeping her safe and happy every day throws a hand grenade through any of my attempts to keep a routine. Taking care of both of us whilst keeping clients and staff happy requires constant, world champion-level juggling!"

Cystic fibrosis shouldn't limit what you're able to do when it comes to choosing a career, and employers should make it their job to help their employees reach their full potential. That said, if you are facing problems at work, need advice or just someone to speak to, contact our helpline on 0300 373 1000 or email [helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk).

### Thinking about the first steps to your future?

Join our evening workshops for 14-18 year olds, funded by BBC Children in Need, in March and April. We'll be covering everything you need to consider when starting work, from how to write a CV and practice interviews to knowing your rights. Visit [cysticfibrosis.org.uk/cfyouth](http://cysticfibrosis.org.uk/cfyouth) for more info and to sign up.



Visit [cysticfibrosis.org.uk/work](http://cysticfibrosis.org.uk/work) to read Laura, Michelle, Rob and Natalie's full stories and to find out more about applying for a job if you have CF and telling your employer about your condition.



# Know your bugs

Meet some of the bacteria that affect people with CF, and see what we're doing to combat them.

## *Pseudomonas aeruginosa*



### Fact file

- ▶ *Pseudomonas* is the most common cause of lung infections in people with CF, but chronic *Pseudomonas* has reduced in prevalence by 17.6% in people aged 16-19 since 2008.
- ▶ A Trust-funded Strategic Research Centre run by Professor Jane Davies at Imperial College is investigating new ways to treat this dangerous bug without antibiotics.
- ▶ We're also co-funding research with Action Medical Research to find out how infections could be targeted earlier.

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

## *Burkholderia cepacia* complex



### Fact file

- ▶ *B.cepacia* is a rare bacteria that lives in damp or wet places like soil.
- ▶ In the 1990s, thanks to research into the rise of *B.cepacia*, it was decided that people with the bug should be kept apart from others with cystic fibrosis. Today, people with CF are recommended never to meet to avoid sharing any dangerous bugs.
- ▶ *B.cepacia* affects just 1.2% of children and 5.2% of adults with cystic fibrosis.

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

## Did you know?



Find out about some "ribbetting" research we're funding into a *Pseudomonas* treatment on page 15!

## Did you know?

We helped to fund a consortium of microbiologists, who are working together to tackle antimicrobial resistance.

### *Mycobacterium abscessus*



#### Fact file

- ▶ *M. abscessus* is the most common form of non-tuberculous mycobacteria (NTM), and people carrying it may be ineligible for lung transplant until they are clear.
- ▶ Trust-funded research by Professor Andres Floto at the University of Cambridge has helped to inform infection-control policies in clinics and hospitals, and the Trust is now funding a second Strategic Research Centre grant to discover new ways to treat the bug.
- ▶ The prevalence of NTM has decreased from 6.1% to 5.8% since 2014.

Search [cysticfibrosis.org.uk/mabscessus2](https://cysticfibrosis.org.uk/mabscessus2)

## Did you know?

We are also helping to fund two research projects looking at ways to speed up infection detection. One is at Manchester Metropolitan University and the other is a collaboration with Professor Davies at Imperial College and Dr Collin Sones at the University of Southampton.

Read more about this research by visiting [cysticfibrosis.org.uk/detectionresearch](https://cysticfibrosis.org.uk/detectionresearch)

# Talking infections - the fight for better lungs



Third-year PhD student Sherine Thomas works on one of our Strategic Research Centres tackling infections in cystic fibrosis, led by Professor Andres Floto. Sherine's research supervisor Professor Sir Tom Blundell sat down with her to chat about her background in research, and her exciting project.



## Professor Blundell: What got you interested in CF research?

Sherine: "During my undergraduate years in a medical university in Kerala, India, I had the opportunity to work in several large hospitals. The major challenge that influenced me was the speed with which infections were becoming more difficult to treat with the few antibiotics that we have. This was especially significant in CF and I became determined to find ways to better address this problem."

## Tell us about your research.

"Lung infections are a major challenge in CF, some caused by bacteria that are highly resistant to current antibiotic treatments. It is really important that we have better options to treat these infections.

"We use a method called fragment-based drug discovery, using very small molecules to define binding sites on proteins that are good targets for new drugs. We build these up chemically, to create potential medicines. This method has been successfully used to develop anti-cancer drugs and we are applying it to address bacterial infections."

## What could your research achieve?

"We could be able to better understand how bacteria spreads, and how we can prevent it

from becoming more harmful. Ultimately, we hope to identify novel drug candidates which can be brought to the clinic as effective treatment."

## How have medical advances helped your research?

"This project has greatly benefitted from the enormous advances in genetic research and bio-computational techniques. Developments in DNA sequencing helped us determine the various bacteria that affect people with CF and identify potential therapeutic targets. Recent analysis of genetic mutations helps us understand how the bacteria spread and what are the most dangerous strains, providing a better guide to the design of drugs with reduced chances of developing resistance."

## And finally - what's next?

"The next step is to use the knowledge gained from the study of non-tuberculous mycobacteria to develop new drugs against other bacteria such as *Pseudomonas aeruginosa*. It will also be interesting to understand in greater detail the various drug-resistance mechanisms that different bacterial species have evolved over the years. All these studies will hopefully equip us with more effective, less toxic treatment choices."



# Libby's story

Libby joined the waiting list for a lung transplant in August 2006. Her journey saw false alarms, setbacks and even an extra transplant, but with her family and friends, she came through it all.

I spent six years on the transplant list and received the lungs on my seventh call. I spent two weeks in ICU with end-stage lung failure, so the transplant team was urgently looking for a possible match. A few weeks after the transplant, my lung function began to drop so they performed a bronchoscopy and other tests and that's when they discovered the lungs had Chronic Obstructive Pulmonary Disease (COPD), a progressive lung condition.

Because of the medication post-transplant, two episodes of a virus called CMV and many years of needing IVs due to chest infections, I required a kidney transplant.

It was very difficult for me to accept that I needed another transplant, but I was always aware that this may happen due to the medication. Dialysis was the hardest part of it all.

A lot of my family and friends came forward to be tested to see if they could donate a kidney to me. They were also shocked that I was having to have another transplant but knew it was necessary, so they gave my husband Chris and myself a lot of help and support through the months.

My transplant team found out Chris was a good tissue match so he could donate his kidney to me, which he did in February 2017.

Life is a lot better now, I am able to do things I was never able to before, like going shopping and taking the dogs for a walk. I still get tired due to the COPD, I just have to do daily physio to help keep the lungs working. I am also able to look to the future and make plans.

**Are you thinking about transplant? Perhaps you know a friend or family member who is going through the transplant journey and want to find out how you can support them?**

**Explore our brand new transplant booklets on our website, and hear from the people with CF who shared their stories with us.**

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



Libby and husband Chris.

"Life is a lot better now, I am able to do things I was never able to before, like going shopping and taking the dogs for a walk."

- Libby



# Meet... Marie Donnelly



Marie Donnelly

*"I encourage families to call the Trust's helpline and ask for advice if I am unable to answer a question."*

Marie is a paediatric CF social worker who works for Barnardo's, the UK's largest children's charity, in Newcastle upon Tyne. Marie works closely with families and young people with CF up to and during transition to adult care and advises them on everything from financial aid to practical support. We caught up with her to find out more about her role.

### So, how long have you worked as a CF social worker?

"I've worked at Barnardo's since 2009, but I've been a CF social worker for about three years now. My colleague and I are commissioned by Newcastle Hospitals Trust and South Tees Hospitals Trust to provide a cystic fibrosis social work service in two paediatric and one adult CF clinic. While I work for the paediatric team, my colleague and I cover the service for each other during leave and absences to ensure no-one goes without the help they need."

### What support do you help to provide?

"I help families with pretty much anything that is making life harder than it needs to be. This can mean helping with access to financial support, benefits or housing, challenging decisions from the Department for Work and Pensions, supporting around issues of safeguarding, helping families come to terms with a diagnosis, linking families to CF psychology services, or even just providing a listening ear when times are hard."

### And how do you work with children and parents?

"In whatever way works best for them, whether that's talking face to face, having creative sessions or speaking over the phone or by email. I see people wherever is

easiest for them, whether that's at home, in hospital or off the ward for a cuppa. It's really important to me that patients and families are in a place they are comfortable in when I see them, and that I fit around their lives as best as possible – they have more than enough appointments already!

"I also work very closely with the family's CF team and offer joint appointments with other CF professionals like dietitians, physios, consultants, nurses and ward staff, where needed."

### What about working with the Trust?

"I refer a lot of people to Julia Hughes, the Trust's Welfare Grants Officer, so that they can get advice about what they may be entitled to and when. When I am dealing with complex issues around benefits and welfare, I check in with Sangeeta Enright, the Trust's Welfare and Rights Advisor. She is always up to date on the latest developments within the welfare system, and her knowledge, experience and generosity with her time are invaluable."

"I also encourage families to call the Trust's helpline and ask for advice if I am unable to answer a question, and I encourage new parents and people with new diagnoses to visit the Trust's website and avoid other, potentially misinformed, websites."

**Want to find out more about CF social workers? Read our interview with adult CF social worker Eileen: [cysticfibrosis.org.uk/socialworker](http://cysticfibrosis.org.uk/socialworker)**

# News in pictures



## Jakub's big match

Five-year-old Jakub, who has CF, had an unexpected Christmas surprise when his local football team, Northampton Town, invited him to be their team mascot for the day at a match against Southend United.



## Building Brighter Futures

The Trust has partnered with BBC Children in Need to create a programme for young people aged 11-25 affected by cystic fibrosis, which includes the funding of Digital Youth Outreach Officer Bahar Mustafa. Visit [cysticfibrosis.org.uk/cfyouth](http://cysticfibrosis.org.uk/cfyouth)

## Sara's got talent

Sara Cuevas Ocaña won CF's Got Talent! by presenting her research into producing CF lung cells in the lab to our online audience at the UK CF Conference. Sara is working on the Strategic Research Centre looking for non-CFTR approaches to CF therapies.



## Ribbeting research

Trust-funded research has shown how a multiple sclerosis drug, glatiramer acetate, could be used to treat Pseudomonas. The drug was originally discovered as a way to get around antibiotic resistance because it has similar properties to frog skin.

## Promise for Orkambi alternative

Two global Phase III trials of tezacaftor and ivacaftor now called Symdeko have revealed this new combination therapy could have comparable effects to Orkambi for people with two copies of the F508del mutation.



## Motorsports-mad Chris slays the Dragons!

Aspiring entrepreneur Chris Frappell took his motorbike maintenance products to BBC's Dragon's Den in February and came away with backing from multi-billionaire business magnate Touker Suleyman.



# Save the date! CF Week 2018

18-24 June 2018

Invite your family, friends and colleagues and join us for our annual awareness and fundraising week.

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





# Òran's Munro bagging

**Cairn Terrier, Òran, along with his co-owner, Chris, is currently on a mission to climb (or 'bag') all 282 Munros – mountains in Scotland over 3,000 ft – in just three years. This feat normally takes climbers around eight years to accomplish! The aim is to support and fundraise for Òran's other human (Chris' partner) Kirsty, and the 10,400+ other people living with cystic fibrosis in the UK.**

As a music teacher and classically trained singer, Kirsty has always understood the importance of keeping her lungs working. She was the inspiration behind the 'breath cycle' project which investigated the benefits of singing for lung function, and last year she took part in the Cystic Fibrosis Virtual Choir (see page 26).

When Kirsty started to struggle to improve her lung function through physical activity, Chris, a Physical Education teacher, devised a cunning plan that would involve a dog!

"As an unofficial therapy dog, Òran has been a huge benefit," says Kirsty, "helping me to overcome mental and physical battles. He is a great companion both during times of illness and when I am able to get out; helping to distract me from the breathlessness and discomfort associated with exertion."

A combination of factors, including the part played by Òran, have had a hugely positive impact on Kirsty's lung function, to the point where doctors have said that they would be happy for the couple, if they were ready, to add another member to the family.





## A challenge was born

“Kirsty once gave me a pocket book on local, low-level hill walks for a birthday present,” says Chris. “These walks soon developed into more adventurous hikes and one day we found ourselves on the summit of Ben Lomond. Looking down through the grey murky skies to Loch Lomond with a sense of achievement and the desire to do more, the challenge was born.”

With 39 Munros completed to date, the pair have experienced glorious sunshine, freezing temperatures with deep snow, and serene green rolling summits. They’ve trudged through squelchy, foot-swallowing marshland, and picked and scrambled their way over boulder fields.

*“As an unofficial therapy dog Òran has been a huge benefit, helping me to overcome mental and physical battles.” – Kirsty*

## Paws for thought

Chris says: “On reaching the summit you really get a sense of being alone and how small you are within the vastness of nature. At the same time you get a chance to reflect on how many amazing people there are, how much they care and how we are all part of something so big.”

With daunting exposed ridge walks along the Aonach Eagach and a 60-foot abseil off the inaccessible pinnacle on Skye, there will be some exciting but, hopefully, not insurmountable challenges ahead.

**Join the adventure by following Òran on Instagram @oran\_cairnterrier or search Facebook for Òran’s Munro Bagging.**





*Coughy break*, shining a spotlight on the talented, creative side of the cystic fibrosis community.

# The accidental vlogger

by Ciara Hillyer

Following the death of a close friend, who also had CF, in 2016 I decided to make a video explaining what CF is. Incredibly, this video was well received not just locally but nationally, including on 'Channel 4 News' and in 'The Times' newspaper. As a direct result, I have become increasingly active in raising awareness of CF by creating videos on a regular basis and sharing my experience of CF through social media platforms. At times, this has been incredibly emotional but it has helped me cope with my grief and my own uncertain future.



**Photographer and YouTuber Ciara Hillyer made the headlines with her first video, and has been inspired to use her passion to raise awareness about CF and help her deal with some personal issues in her life.**

## Unpredictable

Like everyone, I have good days and bad days but as many people will know, CF can be very unpredictable so planning ahead can be difficult and it isn't always easy to be spontaneous. I love, love, LOVE being creative, so the feeling of filming, editing, and completing a video is energising for me.

Due to the unpredictability of my condition, I have pursued this venture at my own pace, mostly from my bedroom where I do all the editing, often with a nebuliser in my mouth! I don't just film though, I have a degree in photography and I'm generally seen with a camera close by ready to capture that image or moment that catches my eye.

## Let's get personal

The videos I make about CF are very personal and honest, and the support and encouragement from others around the world has been overwhelming. I guess seeing my hospital visits, both as an inpatient and also sharing outpatient appointments, has helped some people understand just how complex this condition is to manage, but has also helped them to see what amazing people take care of me and the fantastic relationship that builds up over the years.

I have a few extra complications on top of my CF, including CF-related diabetes and chronic sinus disease, and in my videos I include these aspects of CF as that's what I'm dealing with on a regular basis. It's quite funny seeing and hearing people's reaction when I am talking to my camera. Mum is often close by and she can see their reactions so it's not uncommon for her to explain what's going on and why.





## Raising awareness

My paediatric consultant has used my first video as a training aid for medical students, which is awesome. I have spoken to a class of final year physiotherapy students, and to a room full of families who have children with cystic fibrosis. I have created a video to help young patients through the transition process as they leave the paediatric service to join the adult service and I am a regular guest on my local BBC Radio Bristol station, talking about the NHS, CF and the value of online content.

The more awareness that is raised for CF, the more it will enable a better future for the CF community. At times, yes, it is exhausting, so every now and then I need to take a break from it all and focus purely on myself. I am constantly thinking of new videos to create and I am so pleased that I have been able to offer a little support and hope to the CF community and as long as I am able, I hope to continue.

Cystic fibrosis is a lonely and isolating condition and if my videos make just a little difference to the next generation of CF patients, and offer them hope that they can lead a fulfilling life, then I've achieved something I can be proud of.



## Tell me more

Watch Ciara's latest vlogs at [youtube.com/CiaraHillyerVlogs](https://www.youtube.com/CiaraHillyerVlogs) and view some of her photos on instagram @ciarahillyer.



# Carving out a future

**Celia Lewis is an 82-year-old sculptor from Wiltshire, but she was just 40 when, in 1975, she stumbled across a tree root that would change her life.**

“42 years ago, my husband Frank developed leukaemia. Trying to protect him from infection, we spent our time walking, and one day when we were out I tripped over a tree root.”

Liking the shape of the root, Celia took it home and carved her first sculpture of a crane.

“I had discovered my true medium: wood!”

After her husband died, Celia returned to art, but her focus was on painting rather than sculpture. When she met her current husband Brian, who she describes as a “useful sander,” he persuaded her to start carving again. For 20 years, Celia donated the proceeds of selling her sculptures to different charities, but then her granddaughter Ellie was born with cystic fibrosis in 1998.



Celia carving at home.



*"I am now 82 years old with eight great-grandchildren, so I'm always kept busy, but I still carve most days."*

– Celia

"It was then that I decided to carve for CF for the rest of my life."

Ellie is now 19, and Celia has raised more than £30,000 for the Cystic Fibrosis Trust so far.

"I now have eight great-grandchildren, so I'm always kept busy, but I still carve most days. I have carved various trophies, the most recent being the European Gliding Championships held in 2017 at Lasham in Hampshire. I carved three trophies for the winners and have been commissioned for more this year, a great honour."

For the last 30 years, Celia has exhibited her sculptures at the New Forest Show in July. However, despite all the friends she has made over the years, she has decided that waking up at 4.30am and going to bed at 8pm for three days in a row is "a step too far".

Celia's beautiful sculptures can be purchased at Fisherton Mill Gallery in Salisbury, Wiltshire, and she can make bespoke sculptures for clients with a favourite piece of wood no less than four inches in diameter.

**Do you have a hobby you'd like to share with us?**  
Email [magazine@cysticfibrosis.org.uk](mailto:magazine@cysticfibrosis.org.uk).

# Connecting the CF community

A quick chat in the waiting room. Venting to a support group. Some kind words at a playdate. For parents of children with cystic fibrosis (CF), the risk of cross-infection steals away many of the opportunities for comfort and reassurance that families affected by other conditions rely on.



## Finding support

Having your new baby diagnosed with CF comes out of the blue and can be a huge shock. Parents face a bewildering amount of information, and a whole range of emotions. Health and care professionals provide a lot of information and advice. But, when it comes to reassurance, there is no substitute for the shared experience of other parents of children with the condition.

That's where a scheme we are testing comes in. CF Connect aims to lighten the load by offering parents of children with CF the opportunity to talk on the phone or by email with the only people who really understand what it's like: each other.

We caught up with Sebastian Carter, Support Services Manager at the Trust, to find out more about the people involved in this peer-to-peer support programme.

Sebastian explains: "CF Connect trains volunteer parents of children with CF to support newer parents via email or telephone. For example, if your first child with CF is starting school soon, we might connect you with someone who has a slightly older child so that they can tell you all the things they wish they had known when they were in the same position."

Hearing from someone else who has overcome the challenges you are currently facing can help put things back into perspective when times are tough. Two volunteers took the time to tell us how getting involved with this initiative has helped them give something back.

"The parent volunteers are such committed, compassionate people. They lead busy lives, but still find the time to listen and talk with other parents who may be in need of reassurance, advice and support."

– Sebastian, Support Services Manager





### Meet the volunteers

Jane, from Stockton-on-Tees, is mum to 11-year-old Amelia and eight-year-old Phoebe.

“When my children were first diagnosed with CF, within a day of each other, I was in a state of shock and thought that I would never be able to lead a normal life again.”

Jane believes that cross-infection is the worst part of CF as it prevents people getting together, which can be very isolating and make it harder to come to terms with things. But now, she’s glad she can volunteer her time in this way: “It’s really rewarding to be able to help someone going through a difficult time and use my experiences to help them move forward. I’ve had a number of contacts through CF Connect, which have all been via email. This is very practical for me, as a busy, full-time working mum.”

Another volunteer, Katie, who has a 12-year-old with CF, shared her experience with us. “I signed up because I know how isolated and scared I felt, and after coming to terms with it and living a normal life I wanted to show and tell others that it is all ok.

*“I realised I had nothing to worry about. Being able to talk about things that they could understand fully and actually relate to was so refreshing... The whole family is affected by the diagnosis and I think support is needed for all, so having someone to chat to and ask advice or questions of is great!”*

– April



April and Finley.

"I felt excited before my first call, but also sad that I was about to speak to somebody who was in a dark place. It felt like a huge responsibility as I remember how I felt at the time. I have gained from the fact that I feel like I have helped someone to normalise a scary situation. Once you are out of the initial shock and awe phase, it all just becomes normal life."

### Who's on the line?

April is one of the mums to benefit from the experience of people like Jane and Katie. Her 16-month-old son, Finley, is her first child. She says: "Being hit with the diagnosis as well as being a first-time mum was a whole mixture of emotions! Not being able to have people with CF mix, it felt very lonely."

April says that the best part of being paired up with her CF Connect volunteer is having someone who can fully relate to how she felt.

"I realised I had nothing to worry about. Being able to talk about things that they could understand fully and actually relate to was so refreshing. She was very friendly and open about her story with cystic fibrosis. The whole family is affected by the diagnosis and I think support is needed for all, so having someone to chat to and ask advice or questions of is great!"

*"I signed up because I know how isolated and scared I felt, and after coming to terms with it and living a normal life I wanted to show and tell others that it is all ok"* – Katie

### Get in touch

**Whether there is something in particular that is causing you worry, or you need someone to reassure you that it gets easier, it couldn't be easier to sign up and speak to one of these wonderful people! Just call our helpline on 0300 373 1000 or email [helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk).**

**We'll have a chat with you to find out the age of your child and if there's anything that might make one of our volunteers a particularly good match, such as someone with a child of a similar age.**

# Thank you, volunteers!

Sebastian says: "The parent volunteers are such committed, compassionate people. They lead busy lives, but still find the time to listen and talk with other parents who may be in need of reassurance, advice and support. We'd like to say a huge thank you for that."

"The spirit of the CF community is so important for overcoming the limits that cystic fibrosis places on the lives of everyone affected by it. We couldn't be more proud of our role in helping bring those people together when they need it the most."



## Singing with 'One Voice'

Last year the Cystic Fibrosis Virtual Choir joined 11 other charities on the Choirs with Purpose Christmas album 'Stand Together,' helping to raise awareness and funds for the Trust and the other charities involved. Take a look behind the scenes of this one-of-a-kind choir!

'We All Stand Together,' the album's single, was released in November and brought together 1,400 voices from all the choirs involved in the album. However, the Cystic Fibrosis Virtual Choir was unable to appear together because of the risks of cross-infection. To keep them safe when singing the track and their cover of 'One Voice' by the Wailin' Jennys, producer James Hawkins made sure each singer went into the recording studio separately. The solo performances were then matched together for the exclusive track.

*"Since being part of this, I've thought how nice it would be to sit in a room over a coffee and talk about things with the other singers."*

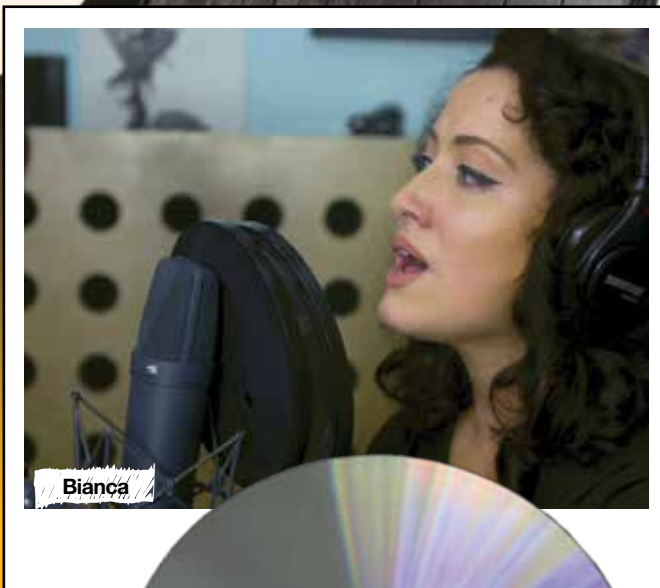
- Bryony



Bianca Nicholas, lead singer in the virtual choir, says: "Whereas all the other choirs were able to stand together and sing, we could not do that, which is ironic when you consider the names of the album and the single. Each of us had to go to a recording studio in London and had a two-hour slot, after that the place was swabbed and cleaned to get rid of any potential germs that could cause cross-infections. It sounds like a lot to do, but it was really worth it. We are all so proud to be able to have worked on these songs."



"Each of us had to go to a recording studio in London and had a two-hour slot, after that the place was swabbed and cleaned." - Bianca



Despite not being able to meet, CF-choir member Bryony Prior said that online platforms have helped her keep in touch with other choir members. Bryony says: "A lot of people think 'Poor you, you've got a disease'. But we're making something positive out of it. Since being part of this, I've thought how nice it would be to sit in a room over a coffee and talk about things with the other singers. Sometimes I message them over Twitter or Facebook and say 'Have you ever taken this or that medication?'"

"...all the other choirs were able to stand together and sing, we could not do that." - Bianca

Choir member Charles Michael Duke highlighted the health benefits of singing: "I started singing when I was five and it really lifts my mood. I also believe it is good for my lungs as it opens them up."

Music Producer James Hawkins, who helped create the album, said at the launch: "We hope that this new choir will help people to understand a little of what it is like to live with cystic fibrosis, and encourage the public to support the charity."

To find out more about the project visit [choirswithpurpose.com](http://choirswithpurpose.com)

Buy the 'We All Stand Together' single by Choirs With Purpose feat. Michelle McManus: [smarturl.it/WeAllStandTogether](http://smarturl.it/WeAllStandTogether)

To find out more about cross-infection visit [cysticfibrosis.org.uk/crossinfection](http://cysticfibrosis.org.uk/crossinfection)

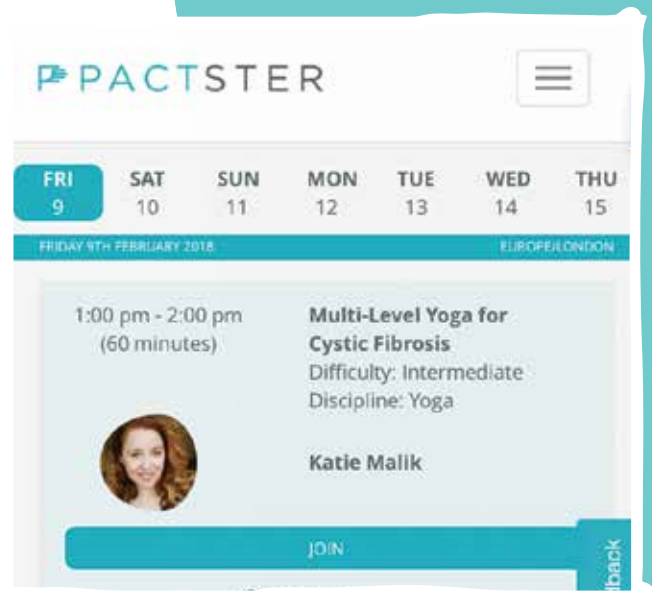


# Get moving with virtual group workouts

Pactster, a specialist in community-based online workouts for specific health conditions, has gone all out to bring the full 'gym class' experience to groups of people with cystic fibrosis. Now, you and your friends with CF can take part in a full timetable of pre-recorded online classes for free. The sessions are CF-specific, focusing on some of the issues that are particularly important for people with the condition, such as improving strength, endurance, posture and flexibility.

Natalie Goodchild, who has CF and is the Chief Marketing Officer at Pactster, explained: "Having the workouts running at scheduled times allows you to 'book them in', which we find helps you stick to a workout plan". Not only that, but you can take advantage of the chat feature in the online 'waiting room' to have a pre- or post-workout catch up, or comment during the session. The workout videos are led by experts, just like a class at a gym, except it's all in the comfort of your own home – so there's no excuse for being late!

Sophie Grace Holmes, a Pactster instructor who has CF, says: "Pactster is a great way for the CF community to workout regularly to keep their lungs healthy and bodies strong around treatments, hospital visits and during hospital admissions."



The screenshot shows the 'GROUP WORKOUT SCHEDULE' page. The table has columns for days of the week: FRI 9, SAT 10, SUN 11, MON 12, TUE 13, WED 14, THU 15. The rows list various workout classes with their durations, difficulty levels, disciplines, and instructors. Each row has a 'JOIN' button.

	FRI 9	SAT 10	SUN 11	MON 12	TUE 13	WED 14	THU 15
10 Minute Upper & Core VIT Workout for Cystic Fibrosis - 10 Second Intermittent HIIT High Intensity Aerobic Interval Training Intermediate Discipline: HIIT						Sophie Holmes	<a href="#">JOIN</a>
Multi-Level Yoga for Cystic Fibrosis Difficulty: Intermediate Discipline: Yoga						Katie Malik	<a href="#">JOIN</a>
Strength and Back Roll - Yoga for Cystic Fibrosis Difficulty: Intermediate Discipline: Yoga						Katie Malik	<a href="#">JOIN</a>
15 Minute Workout for Cystic Fibrosis with Aerobic Interval Training Intermediate Discipline: Mixed Martial Arts						Katie Malik	<a href="#">JOIN</a>
20 Minute Cardio Workout for Cystic Fibrosis Difficulty: Intermediate Discipline: HIIT						Katie Malik	<a href="#">JOIN</a>
10 Minute Upper Body & Core VIT Workout for Cystic Fibrosis - 10 Second Intermittent HIIT High Intensity Aerobic Interval Training Intermediate Discipline: HIIT						Sophie Holmes	<a href="#">JOIN</a>





## Convinced? Here's how to get started!

- 1 Sign up for a Pactster account**  
 – it's free thanks to a partnership with the Cystic Fibrosis Trust!
- 2 Log in**  
 – you'll see the timetable of scheduled workouts on the home page.
- 3 Choose a class and click 'join'**  
 – this will add the class to your list of scheduled workouts.
- 4 Come back when it's due to start**  
 – or show up a little early for a pre-workout chat with others in the online 'waiting room'.

There you have it! Pactster, proving that a little ingenuity goes a long way towards overcoming the practical difficulties caused by cross-infection.

"The group workouts enable us with CF to communicate online and essentially workout together too, which is something that can't otherwise happen due to cross-infection. I'm excited to be part of something that brings everyone together in a positive way and to be able to train and educate others with CF to stay well." – Sophie



Enjoy a range of exercises from instructors with CF by visiting [www.pactster.com](http://www.pactster.com)

# Days in the life

Full-time working mum Emma started her blog, 'Embrace the suck', after her second son Chester was diagnosed with cystic fibrosis. Read Emma's blog at [embracethesuck.blog](http://embracethesuck.blog)

Sharing her journey, and the ups and downs of CF, Emma inspires readers with her candour and 'never lose hope' spirit.



Hospital admissions can be a very testing time as the parent of a small child with CF



Gaining weight can be really important in CF - a cheeky McDonalds when his brother isn't around can help!



Although sometimes he will raid the fridge - luckily this time I caught him before he ate it all!



4



This is why Chester is not left unsupervised in the garden!

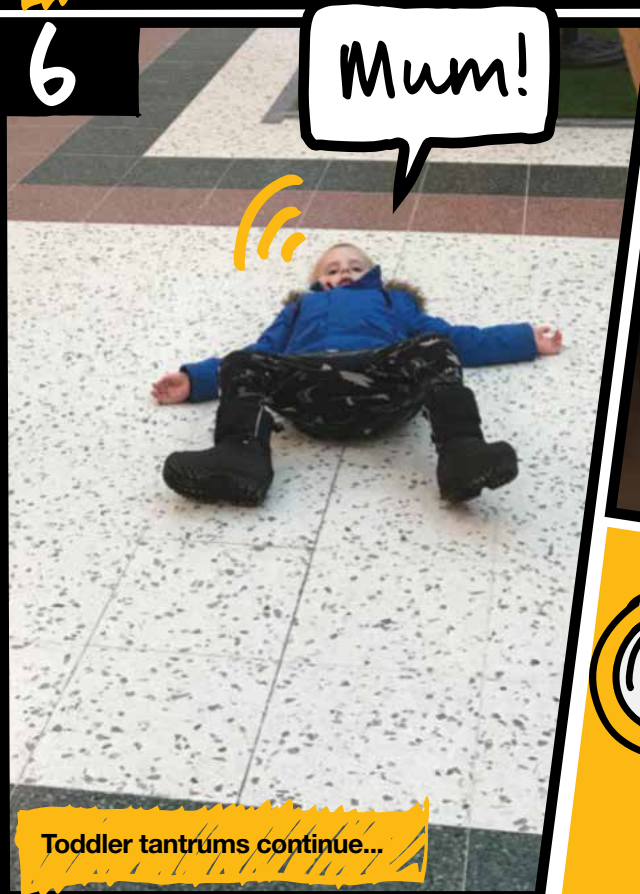
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Refusing to walk – toddler tantrums are something every parent faces.



6

Mum!



Toddler tantrums continue...

7

Chester taking his treatment in hand – CF is only part of who he is.

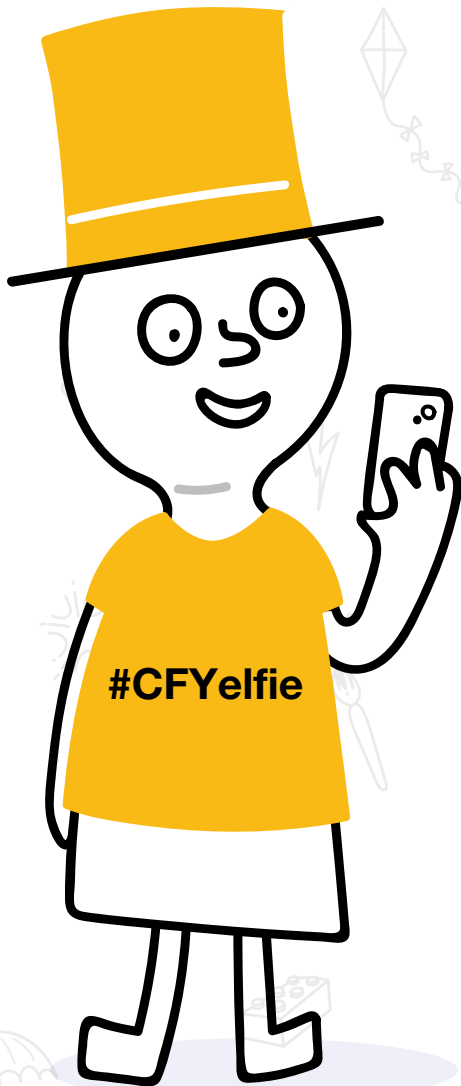


Whatever stage your child with CF is at, you can find information and support in our factsheets and information packs. Visit: [cysticfibrosis.org.uk/publications](http://cysticfibrosis.org.uk/publications)



# Wear Yellow Day

22 June 2018



## Are you ready for Wear Yellow Day?

Organise a yellow-themed event and put on your brightest clothing or accessories. Get your family, friends and colleagues to join in too. Remember to share the photos with #CFYelfie.

Visit [cysticfibrosis.org.uk/yellow](http://cysticfibrosis.org.uk/yellow) to see some of our favourites!

Fighting for a  
Life Unlimited