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CF Life

Issue 11

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Feature

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Fly on the wall

STORMing ahead in research

Fighting for a Life Unlimited

Cystic
Fibrosis Trust

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Issue 11 – September 2021

REGULARS

REGULARS

LIFESTYLE

FEATURES

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Useful contacts

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Events and fundraising enquiries
T: 020 3795 2176
E: events@cysticfibrosis.org.uk

Cystic Fibrosis Trust Helpline
T: 0300 373 1000
E: 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

Welcome to CF Life

In this issue, we look at how the Trust collaborates with a variety of different groups to achieve the greatest impact for people with cystic fibrosis. From investing in and enabling research to building strong relationships with our incredible fundraisers and volunteers. By working together, we can be stronger and more effective.

As people with CF are living increasingly longer lives, we take a look at research studies that will assist with the better understanding and prevention of any age-related CF complications that people may develop.

Former cricketer Stuart Priscott talks to CF Life about his experience with CF. He also shares how he has cycled from John O'Groats to Land's End to both fundraise for the Trust and to improve his fitness.

We meet two recipients of the Helen Barrett Bright Ideas Awards who share how they have used these grants to develop their businesses.

Lastly, we hear from podcaster Kelly Swift who has CF and hosts a podcast aimed at women who are feeling low and anxious, focusing on ways to live a happy and positive life.

The CF Life team

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

Fighting for a Life Unlimited

What you might have missed

Kaftrio and COVID

In May, we welcomed the news that an application for a licence extension of Kaftrio for children aged 6-11, with at least one F508del mutation, has been submitted to the EMA and MHRA regulatory bodies for consideration. This is an important next step in the fight for wider access to CF medicines across the UK.

Whilst this is positive news for many, we also recognise that there are still people with CF that aren't eligible, and we won't stop until everyone with cystic fibrosis has access to the best possible treatments.

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

Research

Trust-funded researchers within our UK CF Innovation Hub partnership have published their work on how *Mycobacterium abscessus* is evolving in the lungs of people with CF. Using mathematical models, the team was able to trace the genetic 'family tree' of each bacterial sample collected. Professor Andres Floto said: "Our findings suggest that you might need to treat the infection as soon as it is identified." Professor Julian Parkhill added: "*Mycobacterium abscessus* can be a very challenging infection to treat – but we hope insights from our research will help us reduce the risk of transmission, stop the bug evolving further, and potentially prevent the emergence of new disease-causing mutations."

Find out more at **cysticfibrosis.org.uk/mycobacterium-news**

Care

The results from the UK Paediatric Patient Reported Experience Survey (PREMs), our UK-wide survey of CF care, are in! You can find the report on our Quality Improvement (QI) webpage: **cysticfibrosis.org.uk/qualityimprovement**

The top three areas respondents wanted to see improvement in were: Communication, Access to the CF team and Listening to Patients. The Trust is working with the Welsh adult CF team to see how their work to increase collaborative care can be shared across UK CF centres. The training they accessed helps empower staff and improve communication for people living with CF whilst ensuring care is decided in collaboration with the patient.

Support

When restrictions started lifting across the UK back in May, the Department for Work and Pensions (DWP) announced that face-face disability assessments for PIP would resume from June 2021. We understand that this will be a gradual move back towards offering face-to-face meetings and we expect that the majority of assessments will still be carried out over the phone. If you are due for a disability benefits assessment, you may have concerns or questions about the move back to face-to-face meetings. We want to support your decisions and make sure you have the information you need. We have factsheets about telephone and face-to-face assessments to help you prepare and know what to expect.

Fundraising

This June saw the Trust's seventh annual Wear Yellow Day. Despite COVID-19 restrictions still being in place, supporters donned their favourite yellow items of clothing and held over 250 events across the breadth of the UK. The Trust also held its second virtual Big Yellow Party hosted by the wonderful Jordy Deelight, along with Jenny Agutter, a DJ, games, and competitions. The community really came together online to celebrate this special day in the fundraising calendar. This year, Wear Yellow Day has raised over £100,000. Thank you to everyone who joined in the yellow fun this year. Find out more at **cysticfibrosis.org.uk/yellow**

Photo: Jess from **@thewonderingdreamer** and daughter Ottilie

The effects of getting older with CF

It is an unprecedented time for people living with cystic fibrosis as CF Registries around the world are showing people are living longer lives. We've recently highlighted progress in research the Trust is funding to tackle some of the existing health priorities for people with CF at our UK CF Conference and in our newly published Research Impact Report. We're also supporting research to help better understand and prevent any age-related CF complications that people may develop.

In May we held our flagship research conference, the UK Cystic Fibrosis Conference, online for the first time. We are delighted that over 400 people joined the conference live to hear about the latest Trust-funded research looking at treating the causes of CF and improving the way the symptoms are managed. For example, we heard presentations on ways to develop medicines for everyone with CF that don't target the CF protein directly. We also heard about research to detect the early signs of CF-related diabetes (CFRD) which in the future may change how CFRD is treated.

Our first Research Impact Report was launched at the conference. It explains the difference our research funding has made since we launched our first research strategy in 2013. It can take a long time from the initial funding of a lab-based research project to the research actually making an impact on the day-to-day lives of people with cystic fibrosis. In the report we shared some examples of the differences that Trust-funded research is making. Our research has provided evidence to reduce cross-infection from Non-tuberculosis mycobacterium (NTM) lung infections in CF clinics. It has also shown the effects of newborn screening on long-term care.

As it can take so much time for research to become a treatment reality, it is important that we're thinking ahead, and anticipating potential new and emerging health priorities for people with cystic fibrosis. As everyone ages, their risk of developing serious health conditions such as heart disease and cancer increases. This will be true for people with CF too. While we celebrate the fact that many people with CF are now living longer and healthier lives, we don't want to become complacent about what getting older with CF could look like. To address this, doctors and scientists have been looking for patterns in health data from people with cystic fibrosis.

Access to national and international registries and increasing global collaboration mean we can identify trends and emerging issues more quickly and ensure we respond in a timely and effective way. This might mean funding lab-based research studies to explain the trends seen in the data.

In the last five years, evidence has started to emerge in the US CF Registry that people with CF are at an increased risk of developing gastrointestinal (GI) cancer, specifically bowel cancer. These early studies reported that more people with CF than they expected are developing GI cancers. In addition to this, people with CF are also developing GI cancer at a younger-than-average age – in their 40s, compared to the average age of the general population who develop it in their 70s. Results from the CF studies so far have also found that the cancer rates are higher in people with CF post-transplant.

We recognise that this article may generate questions about your CF care, and could cause worry or upset. Please have a look at the information about cancer and CF on our website and talk to your CF team if this has raised concerns.

Professor Daniel Peckham, Director of the Adult CF Centre in Leeds, explains "As the number of people living with CF is growing, and people are now living longer, more cases of cancer are likely to occur. We don't know at the moment the exact figures, but we are beginning to collect this data to give us a more accurate and very specific cancer-related picture. In collaboration with the Cystic Fibrosis Trust, we are presently analysing the national cancer registry data and will be reporting the results later this year. Therefore, we will be able to answer these important questions very soon."

What is the Trust doing about CF and cancer?

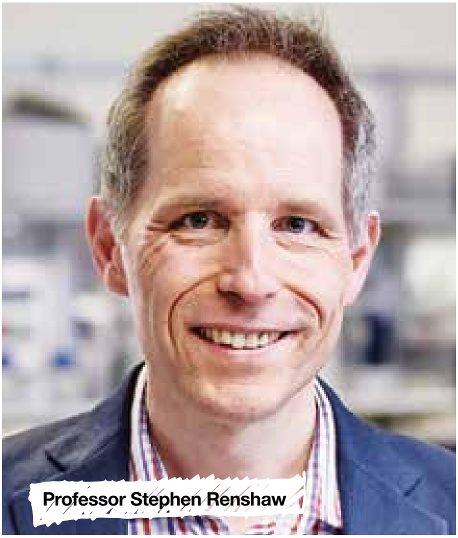
Alongside these registry-based studies, scientists and clinicians are working together to understand why people with CF may be at an increased risk of developing cancer on a cellular level, and what could be done to reduce the chances of someone developing it. The Trust has already played an active role in bringing together a wide range of researchers to begin these discussions by holding a workshop to agree which research areas to focus on to make most progress.

In January, we began funding a Strategic Research Centre (SRC) proposal led by Professor Stephen Renshaw. Using their £750,000, four-year SRC funding from the Trust Professor Renshaw and a new international, multidisciplinary team of researchers formed at the workshop will investigate why people with CF are at a higher risk than expected of developing cancer.

> "As the number of people living with CF is growing, and people are now living longer, more cases of cancer are likely to occur."

– Professor Daniel Peckham, Director of the Adult CF Centre in Leeds.

Researchers at Trust-funded workshop

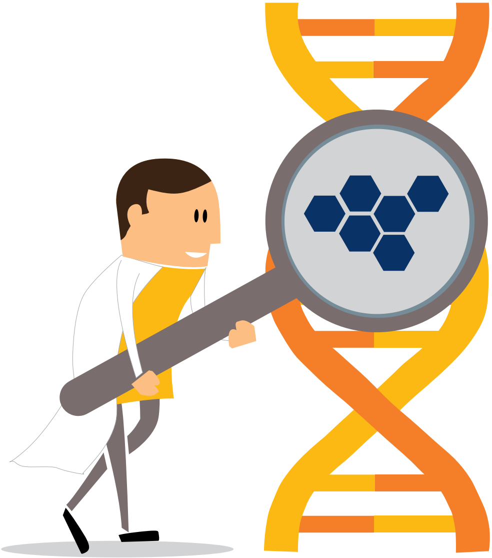

Professor Stephen Renshaw

Preventing GI cancer in people with cystic fibrosis

Within the SRC Professor Renshaw and colleagues will gather more evidence on whether or how disruption to the normal workings of the CFTR protein might directly or indirectly lead to the development of cancer. Towards the end of their SRC programme, they will test whether existing drugs (licensed for other indications) can be used to block abnormal cell processes caused by CFTR mutations and thus reduce these cancer-causing effects in people with cystic fibrosis. This research will hopefully lead to a greater understanding of the role the faulty CF protein plays in GI cancer and may explain why there are higher than expected numbers of people with CF developing cancer – a priority area identified in the original workshop.

"It is only in the last three to four years that researchers in my group have been working on cystic fibrosis. In that time, we have identified a link between the faulty CF protein and abnormal processes in cells," says Professor Renshaw, Sir Arthur Hall Professor of Medicine at the University of Sheffield Medical School.

"The changes we detected could explain on a cellular level why people with CF might be at an increased risk of developing GI-tract cancers. We have brought together a team of experts who could help us answer this question from lots of different angles and put a proposal together. We are really excited about delivering this work for the benefit of people with cystic fibrosis."



> "When I heard about the research into CF and cancer, I was so excited that it was being taken seriously."
>
> – Janine

Janine and her son Alan

Where can I find out more about cancer and CF?

There is more information on our website about understanding the risk of cancer, about bowel cancer screening and about our new lab-based SRC mentioned above. Last year, the Trust was contacted by Janine, whose son had recently died of GI-tract cancer. She was keen to raise awareness of cancer and CF, and was pleased to hear of our research plans.

"My son Alan had CF, and died of GI- tract cancer in January 2020," says Janine. "His wish was that no one else should have to go through what he did. When I heard about the research into CF and cancer, I was so excited that it was being taken seriously. It will help achieve his wish. Knowing this research is underway gives me peace and comfort and hope for the future."

For people like Janine, it is important that we fund research in this area now, to help us do as much as we can to prevent and treat cancer in people with CF in the future.

For more information, visit **cysticfibrosis.org.uk/complications**

STORMing ahead to improve the lives of people with CF

For a consortium of people from the CF community, clinicians and clinical trial researchers, gaining access to Kaftrio was an opportunity to test out a long-held goal – is it safe to reduce the accumulated burden of treatment for people with cystic fibrosis? This is what a new clinical trial called CF STORM aims to find out, with the pilot phase of the trial opening for recruitment earlier this year. We caught up with the trial's co-chief investigators, Professor Kevin Southern and Dr Gwyneth Davies, and the Trust's Involvement Manager Lorna Allen, to find out more.

CF STORM
CLEARING THE AIR


Dr Gwyneth Davies

What is the aim of the trial?

Gwyneth: CF STORM aims to find out if stopping certain daily 'mucoactive' nebulisers (dornase alfa (DNase), hypertonic saline or both) is safe for people with CF taking Kaftrio. This will help provide evidence to support decision-making about these nebulised treatments in the future. CF STORM was developed in response to the CF community's top health priority identified by in a survey conducted in 2017: 'What are the effective ways of simplifying the treatment burden in CF?'. It has been designed with input from people living with CF, their clinical teams, and researchers to be a trial that fits in with routine CF care.

What will taking part in the trial mean for me or my child?

Lorna: Unlike other trials, the CF STORM trial will not require extra visits to the CF clinic. After someone has given their consent to take part and they've been assigned to either stop or continue their mucoactive nebulisers, their CF care will continue as before. When information about their health is shared with their clinical team, this data will also be added to a specially designed and protected area of the UK CF Registry for the trial. During the trial participants will be emailed short surveys at regular intervals to check on their progress. If you have virtual (online) appointments with your CF team, you will still be able to take part.

When will we know if stopping mucoactive nebs is safe?

Kevin: We need to enrol more than 750 people with CF into the study, and we hope to achieve that over the next 18 months. We will then follow their progress over 12 months, so we hope to have an answer by the summer of 2024.

Will this trial benefit people who aren't able to take Kaftrio or any of the other CFTR modulators?

Gwyneth: CF STORM is specifically addressing the question of whether the nebulised treatments DNase and hypertonic saline can be safely stopped for people already established on Kaftrio. Use of these nebulisers in those not taking Kaftrio (either because they are prescribed a different CFTR modulator or no modulator at all) should be continued.

How can I find out more?

For more information on CF STORM please go to **www.cfstorm.org.uk**, or visit **cysticfibrosis.org.uk/trialstracker** and search for CF STORM.

The trial is funded by the National Institute for Health Research (NIHR) and supported by the Trust.

Professor Kevin Southern

My life with CF

As well as continuing his family's legacy as a long-standing fundraiser for the Trust, Stuart is a member of our Involvement Group where his contribution helps inform and influence the work of the Trust and external teams working on research proposals and clinical trials, by sharing his insights into life with cystic fibrosis. He recently reviewed the Trust's new three-year strategy and was invited to reflect on how this supports his own experience of living with CF by talking at our bi-annual all-staff event.

My name is Stuart. I am married with two wonderful girls and work for a cricket charity. I do not consider myself a spokesperson for people with CF; however, there is much in my life that I think will resonate with others.

I'm 50 this year and the Cystic Fibrosis Trust has played a huge part in helping people like me get to this age.

I was born in July 1971 and perhaps in the genetic lottery could have been considered to be unlucky having been born with cystic fibrosis. However, I was fortunate to be born to loving parents and I've enjoyed a stable and supportive upbringing.

Stuart

My confirmed diagnosis of CF did not come until I was 10. My sister Jo was diagnosed as a toddler, and my brother John at a similar stage. This speaks to the relative severity and trajectory CF has taken with each of us. I consider myself to have been very lucky and, for me, my CF has mostly been mild until my late 30s.

When I was born, the prognosis for people with CF was not great, but thankfully we are in much better times and that is down to both medical advances and the work the Trust does.

I was born to a musical family and played piano all my life – it's my sanctuary to switch off and regroup. It has given me a means to express myself and to sustain my mental well-being. My other great passion, which has carried me through life, is sport, and cricket in particular.

Sport has given me an outlet to meet friends, develop strategies to cope with pressure and stay fit and healthy – It made me feel normal, which I think is important – and I even met my wife through cricket.

> "CF did reduce some of my physical capabilities but in some ways helped me to be more resilient..."
>
> – Stuart

> "Sport has given me an outlet to meet friends, develop strategies to cope with pressure and stay fit and healthy"
>
> – Stuart

During my teenage years and early adulthood, I wanted to be a professional cricketer and for a short while was on the books with Somerset. CF did reduce some of my physical capabilities but in some ways helped me to be more resilient, tougher and perhaps a little more tenacious than others.

I married Zoe in April 2004 and we bought a house in Sandford, Devon. It was while there that I began my relationship with Royal Devon and Exeter Hospital (RDE). The CF team have been brilliant and I can report only positive experiences. I am grateful to them for their care and support. Building trusting relationships with your centre is vital and when I later moved to Bristol, I made the decision to stay under the care of the RDE.

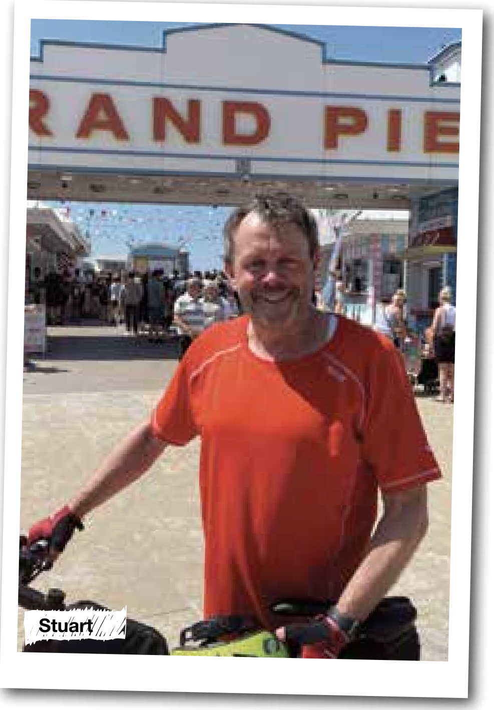
I assumed I wasn't going to have a family, but thanks to IVF, I have two wonderful daughters – I can't imagine life without them. There is a line in the Trust's strategy which says more people with CF will become parents. I don't think it's possible to overstate the importance of this area and how the Trust can support those who want children and those for whom it's not possible.

My health had been stable until I approached 40. I stopped being as active and my lung function began to deteriorate. Not massively, but enough to make things I'd done before without thought to gradually become more noticeable and troubling.

In 2016 I was able to participate in one of the early Vertex trials. I approached the trial with some nervousness but it was empowering to feel that I was 'fighting back' and not accepting what was becoming to feel like an inevitable decline. The difference this has made to my life has been beyond my most optimistic hopes. I have been fortunate and had really positive results, but realise there are still groups who have not benefitted from the new treatment and for whom we must continue to strive.

I've been lucky to work with 'Chance to Shine' the cricket charity since 2005. We work in schools and within the community to give children the opportunity to play and learn through the game. We operate throughout the country in over 5,000 schools and 200 community doorstep clubs. We live in a world where opportunities are not uniform and many do not get to enjoy that which others perhaps can take for granted.

I take my inspiration from my sister who sadly passed away following an unsuccessful lung transplant. She was incredible, courageous and always positive. She was a secondary school teacher for 25 years and lived a full and fulfilling life. I am incredibly proud of the way she found ways to deal with both CF and the debilitating impact of arduous treatments. In some ways, her passing liberated me to do more in the CF space, and prompted me to look at my life and try to take advantage of all the opportunities life throws at us.


Stuart

Since April last year, and in response to the pandemic I shook off the lethargy of many years and decided to get fit. Through daily exercise I've lost around 12 kilos and significantly improved my lung function. To celebrate my 50th year and provide a focus through the long winter and various lockdowns I decided to raise funds for the Trust and Chance to Shine by cycling from John O' Groats to Land's End. Not bad for someone who bought their first bike age 49!

Inspired by Stuart's story? To find out how you can help fundraise for the Trust, please visit:
cysticfibrosis.org.uk/fundraising

Meeting our Branch and Group fundraisers

Back in May we held our first virtual meeting with over 35 of our branch and Group volunteers and dedicated fundraisers who offer support to regional events and help new supporters across the UK. Here, North-West branch members Elena and Michelle, share how they first started fundraising and what they do.

Elena and Michelle

Tell us about yourself!

Elena: We manage the 65 Roses AJ branch, covering North Wales, Cheshire West, Chester and surrounding areas. We're both mums to 10-year-old kids with cystic fibrosis. Michelle has Alyssa and I have Josh, hence the AJ named branch. Michelle and I initially met at a zip line fundraising event about eight years ago. We've been firm friends ever since and share a passion for helping the Trust achieve its goals.

What do you do as Branch members?

Michelle: We do various fundraising events including teddy tombolas at local seasonal fairs, fetes, and festivals. We also sell donated items at car boots, or craft items online through social media marketplaces.

We also attend Trust events such as the London Marathon, Great Strides™, Born Survivor, and many others. This is a fantastically fun way to be actively and directly involved with the Trust. It also allows us to have face-to-face contact with many of the Trust staff and a wide range of their supporters.

Elena: Michelle and I are passionate about our fundraising and awareness raising, due to having children with CF and wanting to raise awareness and funds to help, not only our own children, but anyone else affected by cystic fibrosis.

To get involved with a branch group in your area, visit **cysticfibrosis.org.uk/inyourarea**

Cup of Chi?

Tai Chi enthusiast and Cystic Fibrosis Trust Community Manager Emma, who has CF, shares her helpful insight into why Tai Chi has helped her manage her cystic fibrosis.

I became obsessed with Tai Chi after being lucky enough to take part in a pilot study run at my CF centre. The movements had been adapted especially for people with CF, including variations for standing, sitting, and even those days when CF can make getting out of bed impossible.

A qualified Tai Chi instructor came to my house and taught me the different poses, and we continued classes over Skype. I have continued every day since, building on the initial moves I was first taught. Tai Chi helps clear my mind and lets me focus on my breathing and posture, as well as helping to strengthen my core and I can practice my pelvic floor exercises at the same time.

I think part of the appeal is that I do not need any specialist equipment, which has helped through the pandemic. If I feel I want to mix it up a bit, or follow an instructor, there are lots of YouTube videos to follow and online classes I can join.

That being said, I've never been brave enough to join to class in real life. If you've ever done Tai Chi yourself, or practiced yoga or Pilates, you'll know the risks of passing wind while doing these types of exercise! I don't feel I can inflict that on a room of strangers, but there are classes out there if you are braver (or less smelly) than me!

Talk to your CF team to discuss the different types of exercise that might suit you.

cysticfibrosis.org.uk

Great Strides™

Great Strides™ is back!

After two years of cancellations due to the coronavirus (COVID-19) pandemic, our Great Strides™ series returns – in person, and in time for summer 2022.

- **Great Strides™ Surrey Hills** – 65km route – 11 June 2022
- **Great Strides™ Brecon Beacons** – 40km route – 18 June 2022

So grab your walking boots and we'll see you there (we'll bring the ice creams!)

Find out more at
cysticfibrosis.org.uk/greatstrides

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Bright Sparks

We caught up with two of the recipients of the Helen Barrett Bright Ideas Awards, Jonathan Whittaker and Ellie Wilkinson, to find out how this award has helped their businesses. These awards were established in memory of Helen Barrett, a successful entrepreneur who, together with her partner, set up a gym that is still thriving today.

Why did you apply for the Helen Barrett Bright Ideas Awards?

Jonathan: Starting out in business is difficult, but it's almost impossible without guidance and help. This award opened up channels to experts who helped me on my journey.

Ellie: My friends and family encouraged me to set up a business selling my art, and this seemed like the perfect solution. I loved the idea of a platform to support independent businesses created by people CF too.

> "This award opened up channels to experts who helped me on my journey."
> – Jonathan

What have the Helen Barrett Bright Ideas Awards helped you achieve?

Jonathan: I've been able to sell more products and use the money to place orders with manufacturers, securing lower costs and keeping the products flowing.

Ellie: I wanted to make my art high end. I've been scanning my paintings on a huge fine art scanner and set up my own website. I'm proud of this, because I taught myself CSS coding to make it fit my vision perfectly.


Jonathan

How has the support you have received since winning helped you with your business?

Jonathan: Discussing my ideas and seeing the business issues of other award winners being resolved has helped me learn how to operate my business. It's also helpful to get the insight from others with CF who can empathise with the health issues you have.

Ellie: It was amazing to meet other people in the same circumstances as me and get help with business advice.

What is the best thing about the Helen Barrett Bright Ideas Awards?

Ellie: While I haven't had any discrimination at work because of my CF, it's something I worry about. This showed me that my CF could be just another part of me, with no negative or positive connotations.

What would you say to anyone thinking of applying for the Helen Barrett Bright Ideas Awards?

Jonathan: GO FOR IT! This is a great opportunity to think through your business plan, communicate it and if you're lucky, get funds to boost your business and great advice to propel your entrepreneurial journey.

Ellie: Do it!

To find out more about the Helen Barrett Bright Ideas Awards please visit **cysticfibrosis.org.uk/brightideas**

Remembering Lily

We're remembering Lily Uden, who sadly died in April this year. Lily was one of the first ever employees at the Cystic Fibrosis Trust and, over her incredible 24 years at the Trust, helped to make the charity what it is today, before her well-earned retirement in 1988.


Lily

Lily started at the Cystic Fibrosis Trust in 1964, when the Trust's first director, Ron Tucker, asked if she would join the newly formed organisation. The then called 'Cystic Fibrosis Research Trust' was based in the basement of a solicitor's office on Welbeck Street in central London, given to them by one of its founders, John Panchaud.

Working alongside Ron Tucker, the pair set up a network of parent groups and helped the Trust to reach national status. By raising awareness of CF and increasing the Trust's publicity, Lily was able to raise much-needed funds to support the charity's growth.

The Cystic Fibrosis Trust and the CF Community have grown in ways that could not have been imagined in 1964 – not to mention the incredible number of fundraising volunteers. The Trust would not be what it is today without the hard work and dedication of Lily Uden and her colleagues, and we at the Trust are truly grateful.

Lily with friends Kirsty and Mark

Sandra Kennedy, one of Lily's colleagues from her time at the Trust and long-time friend, had this to say about her:

"Lily had long standing associations and the respect of people with CF, their families, medics, researchers, and fundraisers – many she kept in touch with throughout her retirement.

"Lily enjoyed a good giggle, was good company and was often in on pranks – sometimes the instigator. She was always a caring person, very kind and loyal, and frequently used to say "it's for the families" when explaining her work or her many associations – a mantra used by people she later worked with.

"She will be missed but always remembered."

At the Trust we recognise the importance of remembering and celebrating the life of someone special. Lily's name is in our book of remembrance which you can view via **cysticfibrosis.org.uk/bookofremembrance**. If you would like to know more about our book of remembrance or if there is someone special you'd like remembered please contact Daisy Board, our In-Memory Officer, **Daisy.Board@cysticfibrosis.org.uk**

Coughy break, shining a spotlight on the talented, creative side of the CF community.

Dan on a mission

27-year-old Dan from Worthing tells his story of living with CF through one of his childhood passions: VW campervans.

Living with CF does have a mental toll on me often revolving around how I'm perceived by people. I feel I'm known as the one with 'the condition'. I also suffer with guilt as my experience of CF has been a reasonably healthy one, while others aren't able to live life to the full as much as they wish. I realised that I'd never had a platform to express any of these thoughts, and I wanted to find a way I could raise awareness of CF in my own way. Cars and motoring are a huge part of my life – I grew up in the modified car scene (shout out to my dad and my granddad) and, as a surfer living in Devon, I also own a VW campervan. So, I decided to transform my van into a canvas that raises awareness of cystic fibrosis.

> "As someone who thinks time is the most important currency, this means more than anything to me."

Although I hate being known as 'the one with the condition', I used this to my advantage when designing my van, creating something that blended my personality and interests with cystic fibrosis. The main inspirations were my love of hip-hop, my motoring years, and a lot of CF community slang. The CF-inspired parts of my van come from the 'sixty-five roses' slang term for CF, and patterns designed by @sixtyfiverosesapparel that to me look like medication and a Gucci-inspired nebuliser.

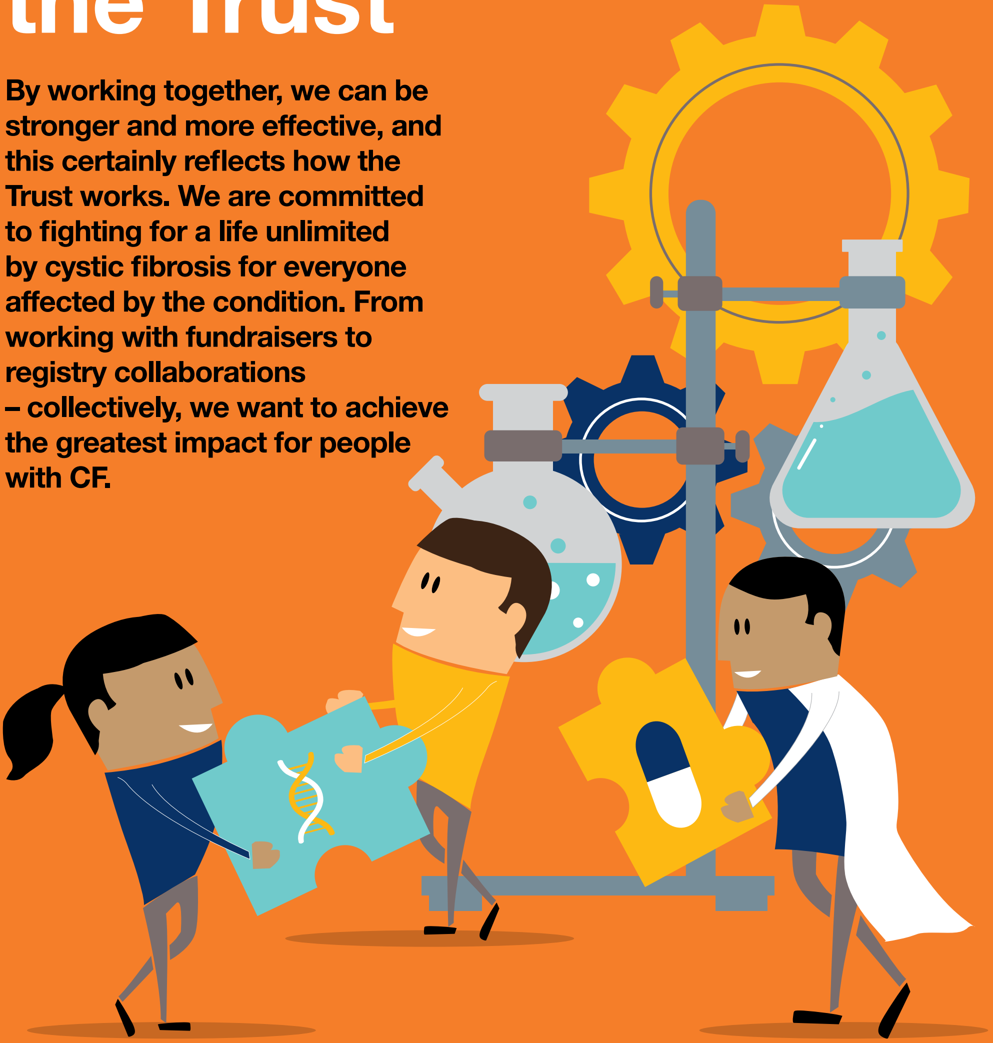
I've made so many lifelong friends since starting this journey with my CF van, from other people with CF, to the people who took time out of their lives to help me. As someone who thinks time is the most important currency, this means more than anything to me. The most important thing is that I can inspire people. On the outside it's very much a CF van, however I want it to stand for more. I want people with any condition to be creative and go after their passions, as I did with mine.

Dan

To find out how you can help fundraise for The Trust, please visit **cysticfibrosis.org.uk/fundraising**

Collaboration within the Trust

By working together, we can be stronger and more effective, and this certainly reflects how the Trust works. We are committed to fighting for a life unlimited by cystic fibrosis for everyone affected by the condition. From working with fundraisers to registry collaborations – collectively, we want to achieve the greatest impact for people with CF.



One area we achieve this is through our ambitious research programme, which enables a collaborative approach to investing in research. Our new Research Impact Report highlights advances that have been made in this field. These are only possible through collaborative and multidisciplinary team working, where each member of the team brings their own unique knowledge and perspective.

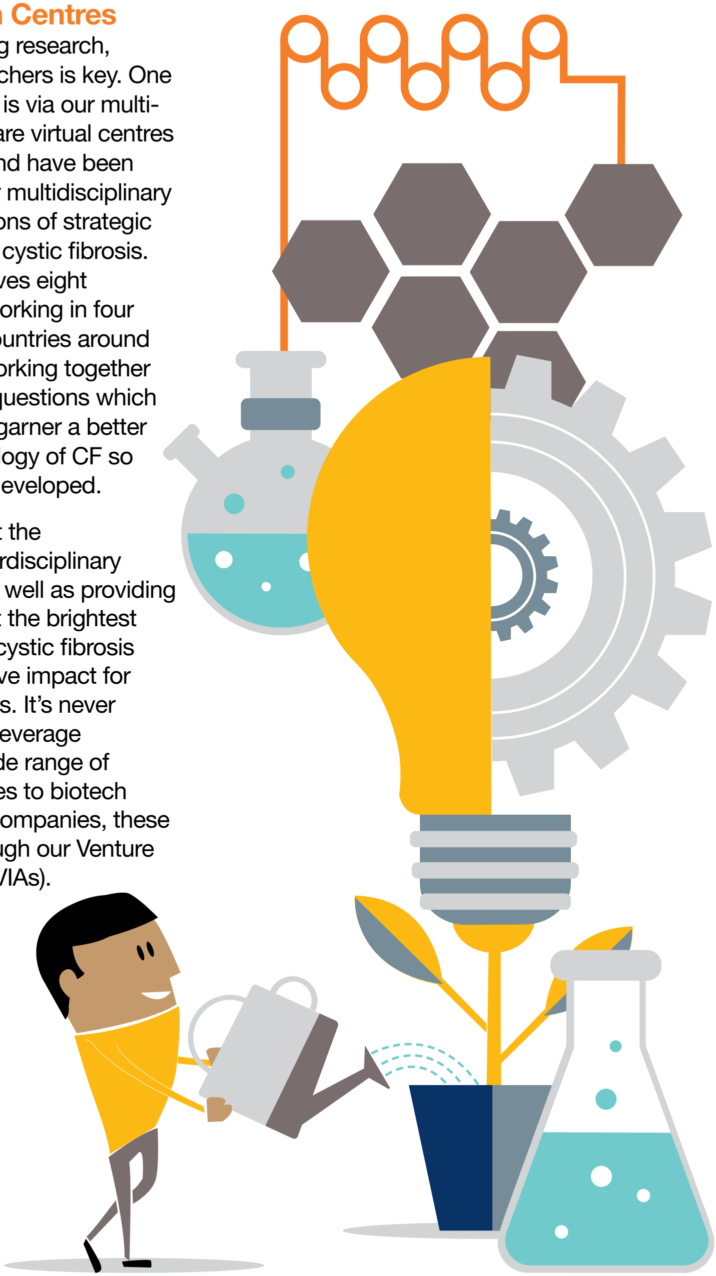
Since 2013 we have created new approaches for conducting research, which include setting up multidisciplinary, collaborative and international research programmes called Strategic Research Centres (SRCs) and co-investing with external funding bodies to progress translational research in CF through our Venture and Innovation Awards (VIAs). We will continue to fund research using these funding schemes.

We co-fund early studies with other charities, universities, and private companies. The results from these are used to secure larger research grants from other funders and encourage conversations between diverse research groups through collaboration. From the £18.4 million that we have invested in CF research; we have leveraged an additional £34.9 million from external partners. This includes organisations such as the Medical Research Council (MRC) and the National Institute for Health Research (NIHR). By stimulating further research in this way, we achieve much greater impact for people with cystic fibrosis.

Strategic Research Centres

When it comes to funding research, collaboration with researchers is key. One way that we achieve this is via our multi-year SRC grants. SRCs are virtual centres of research excellence and have been created to bring together multidisciplinary teams to address questions of strategic relevance to people with cystic fibrosis. Each SRC typically involves eight principal investigators, working in four different cities in three countries around the world. They are all working together to answer key research questions which will ultimately lead us to garner a better understanding of the biology of CF so new treatments can be developed.

These teams will support the development of new interdisciplinary research partnerships as well as providing an environment to recruit the brightest and best researchers to cystic fibrosis research to have a positive impact for people with cystic fibrosis. It's never been more important to leverage the contributions of a wide range of partners. From universities to biotech and biopharmaceutical companies, these projects are funded through our Venture and Innovation Awards (VIAs).



Venture and Innovation Awards

The VIAs allow short-term projects to take advantage of innovative opportunities and are designed to raise additional funding. From a Trust investment of £4.1 million in VIA grants, we have leveraged an additional £17.7 million since 2013. We recently funded VIAs in the areas of tackling the underlying cause of CF as well as understanding and treating the symptoms of CF and lung infection.

Research Grants Review Committee

Our Research Grants Review Committee is an integral part of how we decide what research to fund at the Trust. It's imperative that we have a wide range of people on the committee. In fact, members of the committee include CF clinicians, laboratory-based researchers and people from the CF community. Collectively, they review and discuss proposals to determine which research projects should be recommended for funding. The Research Grants Review Committee is one of the most important collaborations when it comes to CF research as it emphasises the value and impact that research may bring to people with cystic fibrosis.

Aoife, Research Grants Review Committee member, comments:

"The experience of having and living with CF is very different from what it is to have clinical or research expertise. As a person with CF on the Committee, my role is to add the real-life experience; it particularly helps with understanding the value and impact that research may bring to people with cystic fibrosis."

Quality Improvement

The Trust's Quality Improvement (QI) team set up a QI Working Group in 2020, made up of people living with CF, their family members, CF health care professionals and members of the Trust. They meet once every three months online to co-design the Trust's QI Strategy, meaning everyone in the group has equal say on the aims, values, and upcoming projects for the QI team over the next three years. They will also decide how to ensure the Trust's ongoing QI projects – the PREMs survey and Staffing Tool – have maximum impact on improving quality of care.

UKCFMA

We work closely with the UK Cystic Fibrosis Medical Association (UKCFMA) and the co-chairs of the UK CF Psychosocial Group. They provide advice on key issues such as COVID-19 and more.

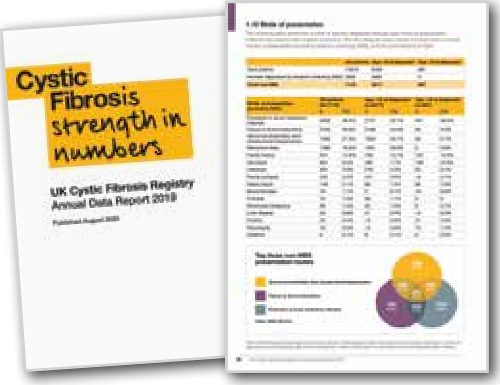
As a result of our relationship with the CF UK Psychosocial Group, we have committed to promoting the valuable work of CF social workers in supporting the CF community and will release new psychosocial guidelines later this year. It will establish best practice in social work provision for people with cystic fibrosis.

UK Cystic Fibrosis Registry

The UK CF Registry, which securely collects vital health data, is sponsored and managed by the Trust. It is a collaboration engine powered by the support of the 99% of people with CF who consent to participate, and all 61 CF centres teams across the UK. By digitally bringing together a community that cannot meet face to face the CF Registry's pooled information can be used by research teams, subject to approval by our Committee which includes people with cystic fibrosis, to discuss important subjects pertaining to CF care.

During the last 12 months alone, the Registry team have partnered with NHS England to track in real-time how people with CF have accessed the NHS differently during the pandemic, and with the SAIL Databank in Wales to better understand vaccine uptake amongst people with CF there.

They have also led a global collaboration of 22 countries around the world to monitor COVID-19 in people with CF to give families and their clinical teams as much information as quickly as possible about the potential impact of infection. The global Registry community doesn't stop there; each year we submit anonymised information to the European Cystic Fibrosis Society Patient Registry, which publishes annual reports showing how CF care is evolving all over Europe. We have also worked closely with Southampton Children's Hospital to obtain a funding award designed to set up a CF Registry in India, which we hope will improve diagnosis and treatment of cystic fibrosis.


Cystic Fibrosis strength in numbers

UK Cystic Fibrosis Registry
Annual Data Report 2019

The UK CF Registry is also becoming a leading clinical trials hub. They are working with with Alder Hey Children's Hospital, running two studies that reduces burden on families, work for clinical teams, and the funding support needed. This group effort between people with CF, parents, CF clinical team members and funders means that vital questions about how to administer antibiotics to babies with CF and whether we can reduce medical treatments for those taking Kaftrio will be answered.

Collaboration in fundraising

The power of collaboration is also evident when it comes to our wonderful volunteers. Raising essential funds together with fundraisers and therefore utilising their support is key to achieving the maximum impact for people with CF. From our seasonal campaigns to our yearly CF Week and Wear Yellow Day, there are year-round fundraising campaigns for our supporters to take part in to support people with cystic fibrosis and their families. Our supporters are a vital part of the CF community who are committed to ensuring that people with CF have access to the best possible support. One example is the Alice Martineau Committee – a fantastic group of volunteers who work so hard for us year-on-year including organising the most incredible virtual Christmas event during lockdown.

Traditionally, the committee works together to deliver an annual fundraiser called Carols by Candlelight, which takes place at St Luke's Church in London every December. But the restrictions of the pandemic didn't stop the volunteers from pulling out all the stops to make the event as amazing as possible.

A birds' eye view of the The Winchester College Chapel Choir recording whilst socially distancing.

We are always looking to work with more amazing fundraisers, so please visit **cysticfibrosis.org.uk/fundraising** to find out more.

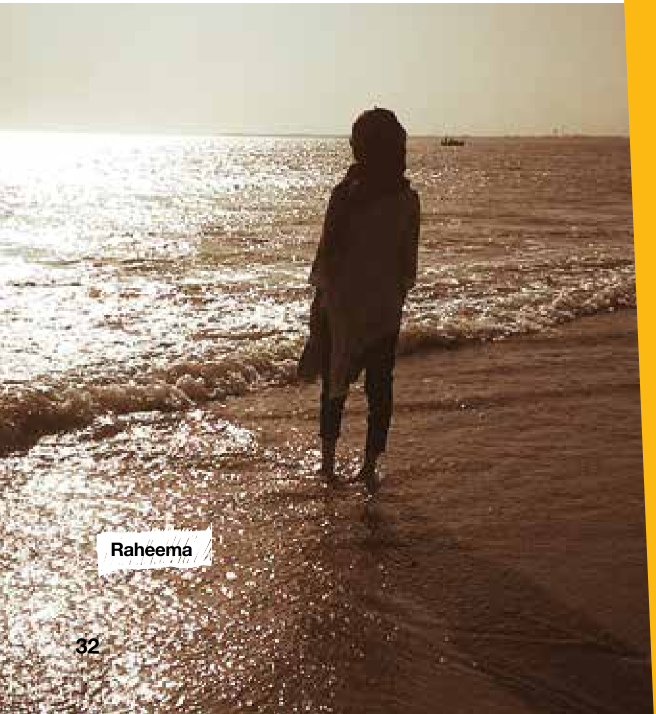
Living with CF in Pakistan

The CF Community is global and never has this community been so important, especially during the global pandemic. After getting her diagnosis at age 18, Raheema shares her experience of living with CF in Pakistan.

> **“It is me who has CF and not the other way around”**

My life took a sharp turn in 2016 and things have been quite different ever since then. That’s when I learned that I had cystic fibrosis.

In March 2016, I was experiencing a fever. The next day, I woke up with a horrible backache on my left side, so bad that I could not breathe. I went to a doctor, who mistook it for gastritis and prescribed me a syrup to calm it down.


Raheema

One month passed: my fever returned, and my weight kept dropping. I was admitted to hospital where I had a lot of tests done, including for cystic fibrosis. That’s when the test results came back positive for cystic fibrosis.

I was blank, clueless, and bummed out. I Googled what CF was (as where else would you go when you have no answers?). I was scared because it said that CF has no cure (yet), and living in Pakistan means that there’s no proper treatment to help control its progression. But I decided that instead of being bummed out, I needed to have strong willpower and fight CF as much as I could.

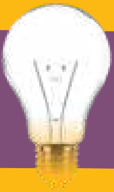
There were times when I used to go days without using my nebuliser because I had to adjust my routine to account for cystic fibrosis. It took me a while to get used to all of this and to accept that if I didn’t follow this routine, my health would deteriorate. That’s when the battle began – and it still continues.

Since my CF diagnosis, I have decided that I won't suffer in silence, which is why I am aiming to spread awareness about CF in Pakistan. My hope is that the taboo of having a genetic disease will one day die down and people in this society will be more accepting toward those of us who suffer from any disease.

I still have days when I feel extremely demotivated and down about life, but then I remember that I cannot let CF dictate my life. It is me who has CF and not the other way around. I am halfway through a Bachelor's degree in social sciences, and every time CF tries to pull me down, I fight and stand back up. That's what warriors do, right? I hope and pray that people with CF in Pakistan receive the life changing drugs for CF that people around US and UK have been receiving.

I want to help make Pakistani society a better, loving, and accepting society for all of us living with diseases like CF and other disabilities. Kudos to all of you silent warriors and stay strong! We're in this together!

> **“I am aiming to spread awareness about CF in Pakistan.”**

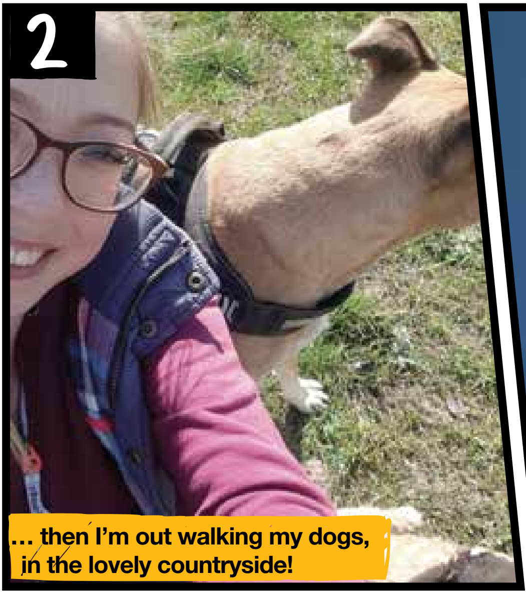


If you have an idea for the next Young Voices or would like to share your views, get in touch on **Twitter @cftrustyouth** or email **cfyouth@cysticfibrosis.org.uk**

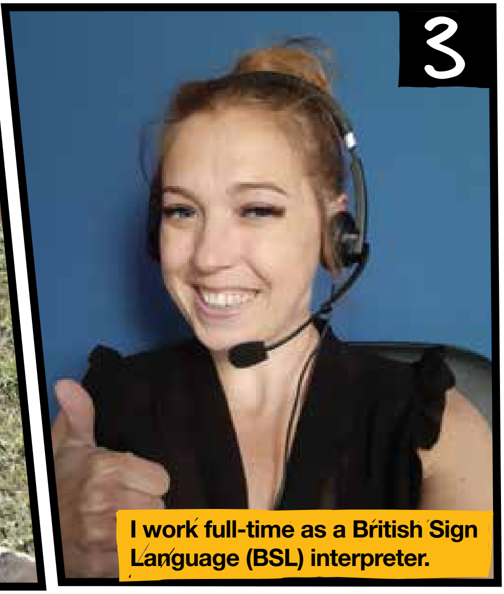
Days in the life

Kelly Swift, who has CF, runs a podcast called 'The Happiness Survival Guide' which is aimed at women who are feeling low and anxious. It focuses on how to live a happy and positive life. Over to you Kelly!

First things first is my morning medication routine…



… then I'm out walking my dogs, in the lovely countryside!



I work full-time as a British Sign Language (BSL) interpreter.

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After work, I start on my podcast recording and editing.

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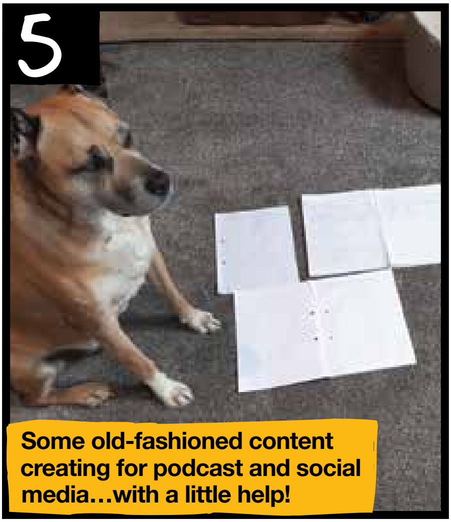
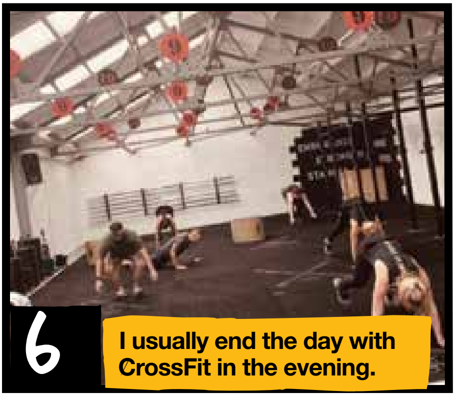


Some old-fashioned content creating for podcast and social media…with a little help!



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I usually end the day with CrossFit in the evening.

To listen to Kelly's podcast, please search for 'The Happiness Survival Guide' via Apple Podcasts.

cysticfibrosis.org.uk

Cystic Fibrosis our focus

Leave a gift in your Will

In these ever-changing times, a record number of people living with CF in the UK are facing new challenges and need your support now more than ever. Leaving a gift in your Will could help bring hope to thousands of people with CF and their families. Anything you can leave will make a huge difference to our work, ensuring every person with CF in the UK can live a long and fulfilling life.

Visit **cysticfibrosis.org.uk/legacy**

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