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CF Life

Issue 2

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Coughy Break

A design for life

Lifestyle

Healthy hobbies & easy exercise

Fighting for a Life Unlimited

Cystic Fibrosis Trust

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

All magazine correspondence should be sent to:

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Welcome to CF Life

It's been a busy time here at the Trust, with some exciting political developments (see p 23), a smashing Christmas video with the amazing Elle (p 5) and of course we bade a fond farewell to Ed Owen and welcomed David Ramsden as our new Chief Executive.

In this issue we are exploring how people's relationship with CF changes throughout their life. Sarah and Olivia take a look at issues teenagers face with managing CF through the eyes of mother and daughter (p 6), and author Tim Wotton shares his survival strategies (p 22).

The experience of being a parent with cystic fibrosis and balancing parenthood with the 24/7 demands of CF proved a hot topic when we asked about it on social media. Your response was so great we felt it deserved a feature of its own (p 13).

And, of course, any discussion about the stages of life, regardless of CF, will involve what happens towards the end. Dr Ruth Keogh has been exploring how people with CF feel about knowing more about things like life expectancy and you can read about her research on page 24. We think it's important to acknowledge all of these things, even if the issues are sensitive, but of course you can skip that part of the magazine and enjoy the rest of it, like a day in the life of YouTuber Siobhan Coles on page 30.

From letting us know what you want to read to sharing your stories, you make this magazine what it is. We hope you like the new issue, and if you have any feedback or suggestions for future content, get in touch at magazine@cysticfibrosis.org.uk.

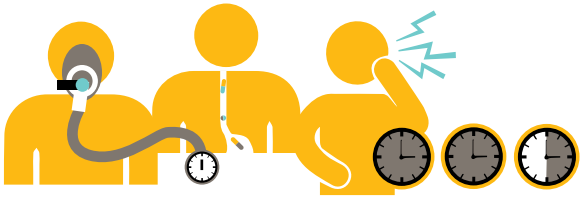
The CF Life Team

Insight Survey

In November last year we launched our first ever Insight Survey, to help us get an impression of life with cystic fibrosis today. We are so grateful that hundreds of you took part to share your experiences, from people living with the condition to family, friends and partners.

We'll be doing a lot more around this survey, which we hope will become an annual event, but in the meantime, here are a few of the things you told us.

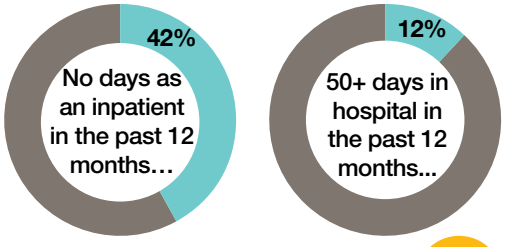
Counting the minutes...

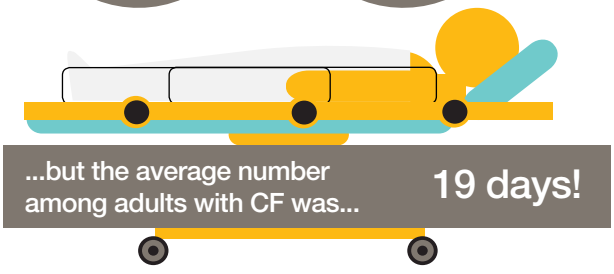


Average time spent on care each day: 150 minutes (2.5 hours)

- **Who spent the longest on care?** A 28-year-old woman
- **Who spent the shortest time on care?** A 19-year-old man

When you're ill, you're ill!





...but the average number among adults with CF was... **19 days!**

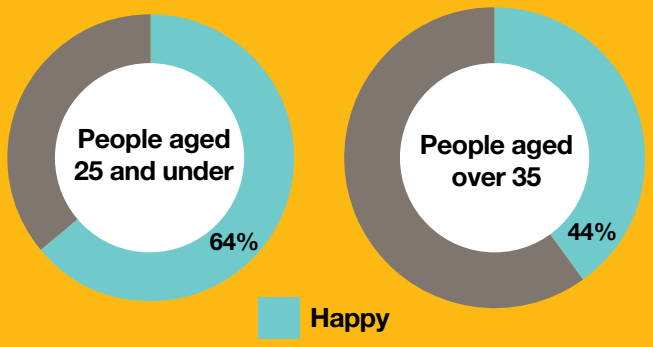
Treatment wins over exercise

Only 46% said they always or usually do the recommended amount of exercise.

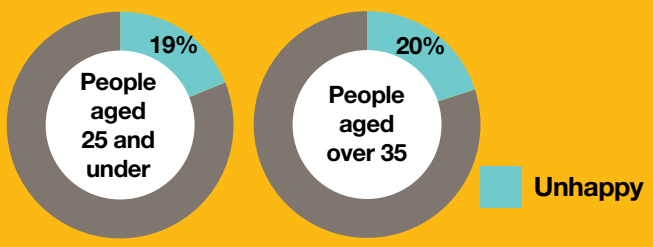
By contrast, 88% said they adhered to their medication, and 77% to nebs. Physio was less easy, at 70%.

It's great being young!

Were you happy, not happy or neither yesterday?

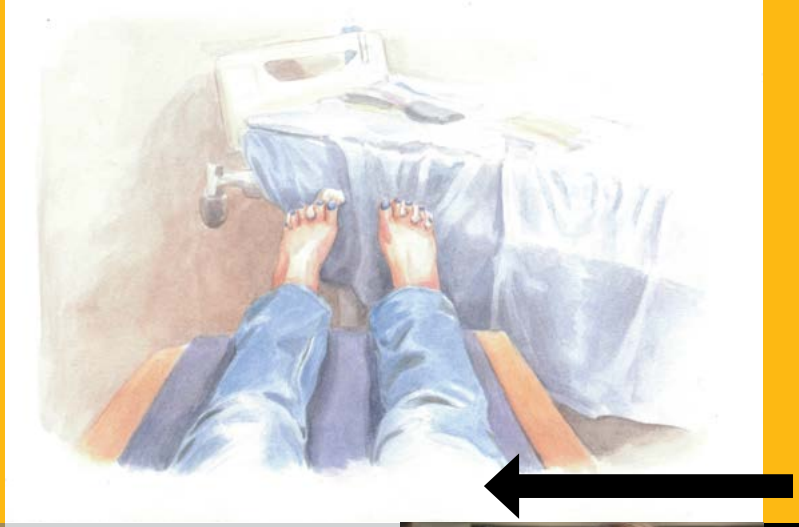


But it's not all bad...



What would you change about your care?

News in pictures



Island Collaborations

Artist Kate Hughes held an exhibition exploring the environment of people with cystic fibrosis on Foulis Ward at the Royal Brompton. Collaborating safely with other people with CF, Kate created beautiful sounds, images and animations to represent a typical stay on the ward.

Boy bags BAFTA

'I Can't Go To School Today: Jasper's story' won the 'Learning: Primary' category of the Children's BAFTA awards. The animation tells the story of Jasper, who has cystic fibrosis, and the daily effect the condition has on his life.

CF's Got Talent

Madalena won our first ever CF's Got Talent at the UK Cystic Fibrosis Conference 2016, presenting her work on one of our Strategic Research Centres in an easy to understand way. Well done Madalena!

Getting interactive

We launched our beautiful interactive body feature on our website to help everyone with an interest in how CF affects the body get to grips with it all. The feature will continue to grow as we add in more sections and videos.

Hello David!

David Ramsden, former BBC Children in Need boss, became our new Chief Executive in December, picking up the mantle from Ed Owen who stepped down after five years at the helm. David brings loads of experience to our fight for a life unlimited.

Keep up to date

The latest news, features and blogs from the world of cystic fibrosis, keeping you up-to-date and in-the-know.

cysticfibrosis.org.uk/news

Elle's a Christmas Star

Ten-year-old Elle stole the nation's heart in a Christmas video for the Trust that showed her writing a Christmas letter to her doctor thanking him for his hard work keeping her healthy throughout her childhood and particularly while she was waiting for a double-lung transplant.

Let's talk about adherence

"Lots of people have asked me why I stopped adhering, and unless you've experienced the situation it's so hard to explain."

– Olivia

When Olivia was a teenager she stopped adhering to her treatments. Now 20 years old, she and her mum Sarah chat about their difficulties with adherence. In a revealing interview, they tell us how they got through it and what advice they would give to parents and young people going through the same thing.

Olivia, aged 11, and her mum Sarah

How did you manage the treatments when Olivia was younger?

Sarah: "When she was very young I would mix most of her medications with yoghurt or jam. As she got older she still couldn't swallow whole capsules, so she would open her mouth and I would literally throw them down her throat. I showed Olivia how to prepare her medications as soon as she was old enough to understand so that she would be able to manage them herself."

Olivia: "I can remember mum doing the tablet throw, she was a good shot! When I was younger I needed reminding to do my treatments and a lot of help, which is normal."

When did adherence become an issue?

Sarah: "When Olivia was about 12 or 13. I felt like a failure. As a parent you feel embarrassed that your child is not cooperating after all their medical team and family are doing to keep them healthy."

Olivia: "Lots of people have asked me why I stopped adhering, and unless you've experienced the situation it's so hard to explain. I knew that it

"As a parent you feel embarrassed that your child is not cooperating after all their medical team and family are doing to keep them healthy." – Sarah

Olivia, aged 13, and her mum Sarah

was so important to do all of my treatments, but I just didn't. And if I didn't know the reason I wasn't adhering, there was no way my mum would know how to get me back on track, which must have been so frustrating for her."

What do you think would have helped you both through that difficult time?

Sarah: "Knowing other CF families well enough to be able to openly discuss adherence would have been a help, but although I was in contact with other CF parents I was reluctant to tell them that Olivia wasn't adhering."

Olivia: "It would have been comforting to know that it's something a lot of young people with CF and their parents experience."

Olivia completing a lung function test, aged 17

"If I didn't know the reason I wasn't adhering, there was no way my mum would know how to get me back on track, which must have been so frustrating for her."

– Olivia

How did your CF team react?

Olivia: "My paediatric consultant was amazing. In the beginning I wasn't honest at my hospital appointments, but as time went on if I wasn't doing my treatments I would admit to it. It's much better than saying you are compliant when you aren't.

"The team at the hospital were great at coming up with ideas. We used different equipment and methods for airway clearance to cut down on the amount of time I was spending doing physio. They really worked hard to help me find a routine that I could stick to."

Sarah: "Olivia's paediatric consultant had seen it all before but didn't preach. I did cover for Olivia at appointments for a while but then I started to think, 'You can't deal with this on your own'."

What are things like today?

Olivia: "I was a grumpy teenager, but me and mum get on really well now. I totally credit her with how well I stayed throughout my childhood because she worked so hard and was so organised when it came to my health. I still have an overflowing red book (Paediatric Personal Health Record) covered in Barbie and Disney stickers to prove it!"

Sarah: "When you have a child with CF you end up cooped up together for weeks on end in a tiny hospital room, so Olivia and I have always been close. We appreciate each other and have a very strong bond and love for each other, due in part to the challenges CF has thrown at us. I am proud to have Olivia as my daughter!"

What advice would you give to parents and young people struggling with adherence?

Olivia: "To young people, I would say be honest. It isn't easy to adhere 100% of the time but if you hide it, it will be harder to sort out."

Sarah: "To parents I would say, don't blame yourself and try to remember that just about every other CF parent has been through what you're going through. One day your child will grow up and understand the importance of all their treatments and why you worried so much.

"And I would say to young people that if you can't talk to your parents, find someone else to talk to. With social media there are loads of ways to find help."

Olivia in hospital, aged 14

Olivia, her mum and stepdad, and their dog Leo

"Olivia and I have always been close. We appreciate each other and have a very strong bond and love for each other, due in part to the challenges CF has thrown at us."

– Sarah

Adherence worries

"We know from our helpline that many families struggle with worries about adherence. Our advice is to contact your CF team - they are very used to supporting families when a child is struggling with their treatment regime, so don't be afraid to ask for help. Depending on the age of your child, support might be available from CF psychologists, through play therapy or from other members of your CF team.

"The Cystic Fibrosis Trust provides a range of support services that you might find helpful including our helpline, the online forum and CF Connect, which is a service that puts you in touch with other parents who have had similar experiences."

Becky, Support Services Manager

Contact our helpline on 0300 373 1000

Registry data - shaping a better tomorrow

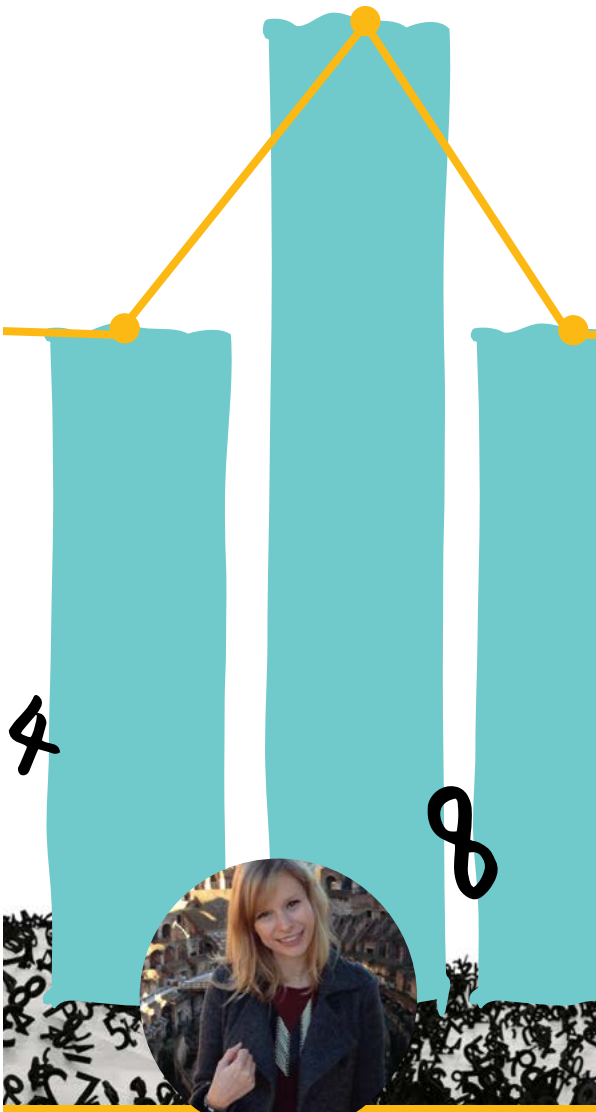
By Rebecca Cosgriff, Registry Lead

It's been 10 years since the Cystic Fibrosis Trust began managing the UK Cystic Fibrosis Registry and, thanks to the support of our amazing community, the data it holds has never been more important. It shows us what incredible changes have been taking place for people with cystic fibrosis (CF) and how things might look in the future.

Registry data shows that since 2007 the number of people with CF in the UK has increased by 33%, and the median predicted survival has risen by 10 years. Registry data also helps us to look forward - a report written by Professor Diana Bilton and Dr Ruth Keogh estimates, through the Registry, that the adult CF population will increase by 32% by 2026.

Thanks to the Registry, important discussions are starting today about how CF care can be shaped to meet the needs of people with the condition tomorrow. Registry data may even hold the key to people with CF gaining access to new medicines. By collecting data about new medicines for people living with CF, we can provide the NHS with meaningful evidence to assess the long-term effectiveness of new medicines.

Projects like My CF Registry, developed through one of the Trust's Strategic Research Centres (SRCs), will also give people with CF the opportunity to add their own data to the Registry, enhancing how we use it and what we can learn from it.



"Registry data may even hold the key to people with CF gaining access to new medicines." – **Rebecca Cosgriff**

Dr Siobhán Carr, one of the Principal Investigators on the 'Harnessing data to improve lives' SRC, spoke to CF Life about the CF-EpiNet Study, My CF Registry and opening up access to personal data.

"Our SRC has several research groups from around the UK and in Canada working together on collections of anonymised data from the Registry to explore the impact of various factors on medical outcomes in people with cystic fibrosis.

"A major part of the study is developing the My CF Registry portal. This will start with a Patient Reported Outcomes (PRO) research study: 'Living with CF'. In 2017 we want to invite all adults with CF in the UK to fill in three online questionnaires: a UK CF Quality of Life survey, a generic quality of life survey that is used by the National Institute for Health and Care Excellence (NICE) and a third that is a four-point 'wellness score' used by the government within the general population. This 'wellness score' is new to CF and hasn't been used in a group of people with a specific medical condition before.

"After reading a patient information sheet, adults with CF will be given a unique code at their CF centre annual review. This code will allow them to go online and access the 'Living with CF' study questionnaires on the My CF Registry portal. Once they have consented, the survey takes about 15 minutes to complete. We are currently piloting this PRO research project in Swansea, Sheffield, Southampton and the Royal Brompton Hospital, and the study will be the first of its kind.

"The My CF Registry portal has been developed so that an individual's PRO data can be linked to annual review clinical data entered by their CF centre. We have the exciting possibility of incorporating the linkages of these two types of data into future studies, and we also have the potential to further develop the My CF Registry portal to enable people with CF to view their own personal data. It would be one of the first registries to enable this to happen."

"We also have the potential to further develop the My CF Registry portal to enable people with CF to view their own personal data. It would be one of the first registries to enable this to happen." – **Dr Siobhán Carr**

So what exactly is the Registry?

The UK Cystic Fibrosis Registry is a database sponsored and managed by the Cystic Fibrosis Trust that records vital data on the health, treatments and demographics of people with CF across the UK. Find out more and read our Registry reports at **cysticfibrosis.org.uk/registry.**

Meet... Sarah Denford

Dr Sarah Denford is a health psychologist and research fellow at the Children's Health and Exercise Research Centre at the University of Exeter, who is working on our Strategic Research Centre (SRC) investigating exercise promotion in adolescents with cystic fibrosis (CF). We caught up with her to find out more...

Dr Sarah Denford

"We know that physical activity can have huge health benefits, but we also know it has psychological and social benefits like improved self-confidence and lowered stress levels."

– Dr Sarah Denford

Hi Sarah, can you tell us a bit about the SRC?

"A big focus of the research is measuring different intensities of physical activity and exercise. Clinicians play a really important role in promoting physical activity, sport and exercise, but they don't always know what to prescribe. We're trying to work out what levels of physical activity are most beneficial to people with CF, and one of the first things we're going to do is an interview study with clinicians to find out what barriers there are to promoting it."

What's your role?

"I'm focussing on the psychology of adolescent exercise behaviours. There are loads of examples of people with CF doing amazing things, but on average people with the condition are less active than the general population. My work is about exploring the reason for that gap, and discovering what we can do to encourage people to become more active."

So, why is the transition period such a crucial time for young people with cystic fibrosis?

"During transition, young people go from relying on their parents to becoming independent, and move from child services to adult services. Adolescence is a tricky time, especially when you factor in all the responsibilities and worries of a medical condition."

"It's also a time when habits are formed for later life. If we can encourage people with CF to become active in adolescence, then those behaviours can continue into adulthood."

What are the benefits of staying active?

"We know that physical activity can have huge health benefits, but we also know it has psychological and social benefits like improved self-confidence and lowered stress levels. It's been linked to reductions in depression - it's sort of a wonder treatment!

"There is evidence to suggest that some of these psychological benefits are linked to improved medication adherence, although further research is needed to explore this link."

And finally, can you tell us what the next big thing is for the SRC?

"We're working on a website called Active Online, which helps people with CF make and meet physical activity goals. The website has already been piloted in one of our SRC centres in Melbourne, and we're trying out the same web-based platform in the UK, but on adolescents."

Find out more at cysticifbrosis.org.uk/activitysrc

Striking the balance

Advances in treatments for cystic fibrosis (CF) mean that starting a family is increasingly an option for people with the condition. Last year we asked parents with CF to share their experiences of juggling childcare and hospital admissions. The response was overwhelming.

Parents across the UK and abroad contacted us, not just about hospital admissions, but about everything that being a parent with a life-limiting condition entails.

Amy and Evie

Together and apart

While the experiences of parents with CF are all different, one overwhelming theme stood out: how isolating hospital admissions can be.

Yael, mum to 13-year-old Harry and six-year-old Oliver, spent the first six weeks of her eldest son's life in hospital after her portacath became infected.

"I tried to keep Harry with me in hospital, but soon my milk dried up and I was receiving IVs that made breastfeeding unsafe. Harry went home to my family. Being separated from my baby was more horrible than I care to remember."

Amy has a two-and-a-half-year-old daughter called Evie, who has an 'inconclusive diagnosis', of cystic fibrosis. For Evie, this means she has a lot of the same symptoms as a person with CF, but using standard tests her doctors are unable to officially diagnose her with cystic fibrosis.

"Evie's CFTR protein works normally, but like a person with CF she does physio and has had three admissions for IVs in the last year. She has been on permanent nebulised antibiotic therapy two times a day every day since she was 18 months old, and takes liquid antibiotics three times a week. I am colonised with two strains of Pseudomonas and so is Evie – it is likely that this was caused by cross-infection."

"Looking after myself and my children is equally important – without my health I would be no use to them. They are the reason I get out of bed even when I feel unwell."

– **Yael,** mum to Harry and Oliver

When it comes to hospital admissions, Amy has faced some challenges.

"Evie's last two admissions were really hard on my health. As she's young she found it very traumatic and wanted me around her constantly. On her last admission she had a central line and wasn't allowed to leave the ward."

Knowing that she couldn't leave Evie alone on the ward to go and get food for herself, on days her family were unable to visit Amy had to rely on overnight feeds through her gastrostomy tube to keep her calorie intake up.

"And then I ended up on IVs too, so we were a right pair!"

For James, dad to two-and-a-half-year-old twins Isobel and Logan, not being able to see his family while he's in hospital is incredibly hard.

"I never used to mind having some alone time, but like most things this all changes when you have kids! I don't currently allow my children to visit me in hospital. I know I'm sick and that the upcoming months or years will be incredibly hard

James and his wife with their children, Isobel and Logan

Amy and Evie

Interested in Amy and Evie's story? Find out more about inconclusive diagnosis by visiting **cysticfibrosis.org.uk/inconclusivediagnosis.**

on my family, but my children come first and I'm happier knowing that they are enjoying their days doing what kids should be doing."

The challenges of childcare

All the parents we spoke to have faced their share of adversity. Hardly a year after Harry was born, Yael's hospital stays were becoming permanent, and she was on a breathing machine 24 hours a day.

"When I was strong enough Harry would come up to visit, but when it was time for him to leave he would scream and call out for me, which broke my heart."

For James there are "a-million-and-one things" he struggles with. Some of them are small ("Carrying car seats is body-breaking!"). Some of them, he says, are much bigger.

"The most difficult thing by far is realising that I might not be there to see my children go to primary school, let alone walk them down the aisle. Knowing I will be ripped away from them when they are still so young eats at me every day."

"I don't currently allow my children to visit me in hospital. I know I'm sick and that the upcoming months or years will be incredibly hard on my family, but the children come first."

– **James,** dad to two-and-a-half-year-old twins

For Amy, the hardest things is watching her daughter suffer.

"It's terrible watching Evie go through the pain of IVs, screaming when she has to take horrible antibiotics, getting so distressed that she gives herself nosebleeds, or clinging to me when she sees a doctor, saying 'don't put needles in me or Mummy!'"

Totally worth it

Despite the difficulties of being a parent with CF, the people we spoke to all said the same thing – when it comes to their kids, the struggle is worth it.

For all the challenges, Amy says that she and Evie manage together.

"When it comes to CF, Evie knows no different. Mummy does nebs, Evie does nebs. Mummy goes to hospital, Evie goes to hospital!"

When her son was almost two years old, Yael received a double-lung transplant. Then, after eight years of taking highly toxic anti-rejection medication, she developed end-stage kidney failure. Her brother generously offered his kidney, and was a perfect match.

By the time Harry was five, Yael and her husband decided to try for another baby using a surrogate.

"After a long and tearful journey, we met the surrogate who would carry our second son, Oliver. Life as a mother has never been boring. Looking after myself and my children is equally important – they are the reason I get out of bed even when I feel unwell.

"Recently I asked Harry what it's like having a mother with cystic fibrosis. He replied, 'I think it's normal, I don't know any different!'"

We want to support everyone in the CF community as best we can, and we know that at times things can feel difficult or overwhelming. If you feel like you're struggling there are lots of ways you can find advice and information. Call our helpline on **0300 373 1000** or visit our forum at **cysticfibrosis.org.uk/forum** to talk about the issues that matter to you.

If you are thinking of starting a family, take a look at our fertility resources to find out more about being a parent with cystic fibrosis: **cysticfibrosis.org.uk/fertility**.

Snap up a bargain!

You really are a creative bunch! We love to hear about your projects and support you with your fundraising. To snap up one of these treats, browse even more options or tell us about your own money-making masterplan, just search 'supporter merchandise' on our website.

Tote bags and badges

The South Lincs CF branch of the Trust is made up of families of children with cystic fibrosis and has been arranging fundraising and activities to support the local CF community since 2012.

The duck is a symbol of remembrance for Helen Bond, a founding member of the branch and an avid collector of rubber ducks! She lost her battle to CF in December 2014, aged 28. The continued use of the duck keeps her memory alive and helps spread awareness of cystic fibrosis.

"We wanted to create a lasting memory for our friend while raising vital funds to help others, like our children, suffering with cystic fibrosis (CF). The duck became a perfect way to incorporate the yellow Cystic Fibrosis Trust colours and a lasting memory for Helen.

"We decided to design a bag as something we could sell at any event, and designed it to include the fact that 1 in 25 people are a carrier of cystic fibrosis. We wanted to help raise awareness of CF, and thought this was a great way to get people talking more about it!"

– The South Lincs CF branch

The South Lincs CF branch of the Cystic Fibrosis Trust

Drew Turner

Thinking football

"Try your hardest to get your child involved in some sort of sport and hope they love it too!"
– Geoff Turner, parent to Drew

Thirteen-year-old Drew Turner has cystic fibrosis, but that doesn't stop her fulfilling her goals in life – including playing football. What started out as a hobby has become a passion, and her hard work, dedication and talent has been rewarded with an invitation to the Regional FA Elite Camps, the next step on the path to representing England Women at Under 15.

Her family are very proud of what she has achieved with her extra workload of medication and physiotherapy; Drew is an example of how cystic fibrosis should not dictate who you are or limit what you can do.

Between them, Drew's Dad Geoff and football coach Martin Lee Herdman came up with the idea to write a book to raise funds for the Trust, and here it is! A football coaching/training handbook full of inventive ideas on how to get your players thinking about and enjoying training sessions. It replays famous moments in football and enables you to create new, fresh sessions.

Sport the leggings

"We love working with the Cystic Fibrosis Trust and love that we can help raise awareness as well as make our designs personal to the person wearing them. Your own journey is as important as the bigger fight and we hope to help you share a little bit of that with others when fundraising, running, cycling or just wearing day to day."
– Kath Grimmitt, The Power of Greyskull

Emma Hughes originally had these leggings made to raise awareness with a personal touch while training, fundraising and taking on her many challenges. She had the idea to approach Kath about creating some exclusive designs to raise funds for the Trust.

The Power of Greyskull is a small sportswear company based in Cardiff that designs and makes all of its clothing in-house. They have a fantastic range of Trust-inspired leggings; they're guaranteed to get you noticed at any event, and £7.50 from every pair is donated to the Trust.

Emma Hughes' bespoke leggings

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

Meet Ute, our guest designer

Ute is a 26-year-old Design researcher who lives in Glasgow. Ute's sense of smell has been damaged by medication, however she can still smell pancakes from adjacent rooms and would happily forego most engagements and/or work for the chance to hang out with puppies instead!

Given her profession and area of study we knew she'd be pretty nifty with design software so we put her to work designing her own coughy break spread in collaboration with the Trust's Design team.

I am a graduate of the Masters in Design Innovation at the Glasgow School of Art.

I have lived with cystic fibrosis for 26 years. It has been wonderful, if a little breathless.

I have also lived with the healthcare systems of several different countries, which has not always been wonderful, but has kept me alive.

Hello.
My name is Ute.
I AM A DESIGN RESEARCHER LIVING IN GLASGOW.

DESIGN AND ME

Design is evolving and transforming at the moment. It's no longer only about making pretty graphics or products, it is becoming a practice that explores the future and generates knowledge.

My background is actually in anthropology and sociology, so I am interested in context, cultures, and systems. What I love about design is that it can move such research from analysis - from revealing how things are - towards synthesis - suggesting how things could be.

Looking in depth at what is happening and where things are going throws up big questions, both exciting and troubling ones. And I believe design is about addressing them, about opening larger discussions, challenging and critiquing what is sometimes seen as inevitable, and uncovering and shaping new ways to move forward.

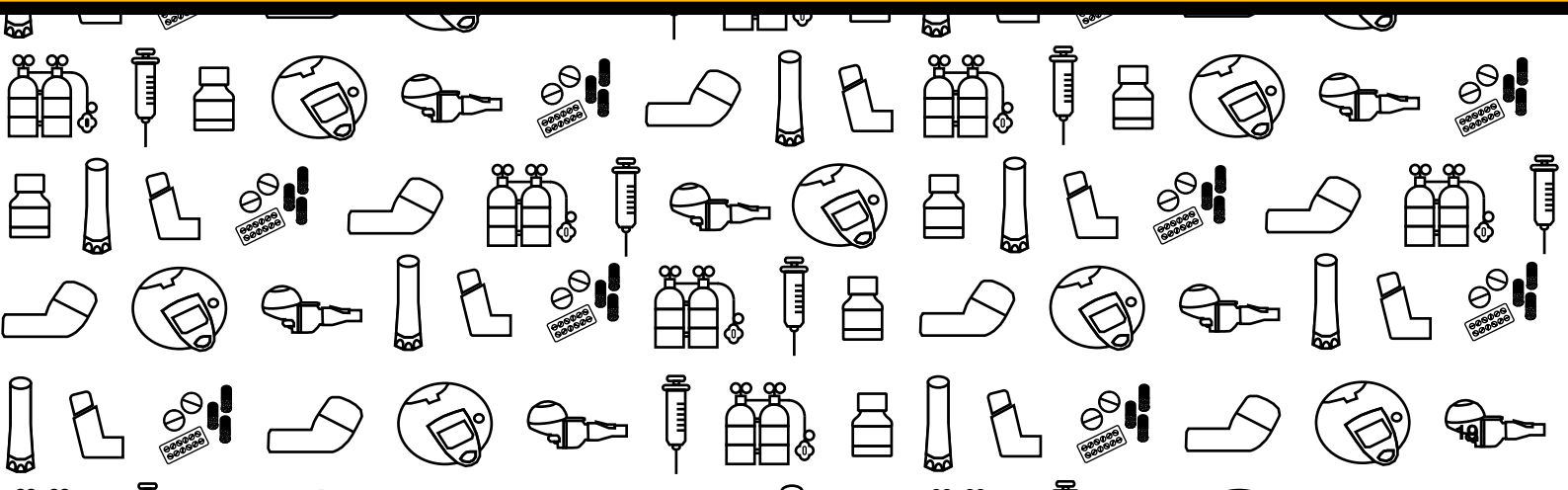
SALTY LIVES

My Masters project 'Salty Lives' was an experiment in how design might unravel, interrogate, and re-envision healthcare. I used living with cystic fibrosis as a lens to look at the wider questions relating to the future of healthcare in the UK.

Living with cystic fibrosis means a complex and life-long treatment regime, frequent hospital stays, personal involvement in large parts of our own care, and new possibilities for precision medicine. In short, we are 'extreme users' of the healthcare system.

For me, living with CF provided an opportunity to question how we might live with chronic illness in future as a society. And how design might be used to re-imagine the cultures, institutions and systems that shape our world - and in this case, make up healthcare.

More at www.uteschauberger.com



Mindfulness and meditation

Dr Ann-Marie Golden, an experienced health psychologist, cognitive scientist, therapist and mindfulness facilitator, introduces the practice of mindfulness.

For all of us, breathing must be considered one of the most important things. I am frequently asked why on earth anyone with cystic fibrosis (CF) would want to focus on theirs when they often report that each breath is a struggle.

But mindfulness isn't just about breathing; it's about getting to know yourself more intimately and learning different ways of taking care of your mind and body in order to introduce more calm.

My favourite definition of mindfulness is: "simply being aware of what is happening right now without wishing it were different; enjoying the pleasant without holding on when it changes (which it will); being with the unpleasant without fearing it will always be this way (which it won't)" (James Baraz).

As well as managing a variety of difficult symptoms, the CF community reports high rates of mental health issues which can lead to lower quality of life, increased hospitalisation, poor adherence to treatment and more.

Dr Ann-Marie Golden

"Mindfulness has taught me how to pay more attention to my body and be aware of the various symptoms of CF each day, and because of that I'm better able to make decisions about my health."

– Oli Lewington

To take better care of ourselves we can choose a point of focus that we can direct our mind to with intention and effort, learning how to be present in the moment, such as:

- **Bodily sensations** – notice any physical sensations in your body; what they feel like, describing them to yourself, notice that if you stay with a feeling like discomfort for a few seconds it may subtly change.
- **Sounds** – close your eyes and notice the sounds in the environment around you, where they are, if you like them. Try to resist labelling them and just be curious as to what properties they have, like pitch and quality.
- **Music** – pick a song and pay attention to the sound, how it changes, the beat and how the lyrics can have an impact in that moment.
- **Writing** – we can anchor ourselves in the present by writing a stream of consciousness and often be surprised with the outcome.

Although the popularity of mindfulness has led to it being described as a solution to all our ailments, it's important to realise it is a different way of approaching a difficulty that may offer momentary respite and in the long run improve our quality of life. For a more detailed article go to cysticfibrosis.org.uk/mindfulness.

Be your own champion

Tim Wotton, award-winning author of 'How have I cheated death?', is 45 years old and has cystic fibrosis. He appreciates what living a life unlimited could look like and here, he explains some of his survival strategies...

I have learnt so many physical and mental lessons over the years – what works (and doesn't need fixing), what made me feel really unwell (and is not to be repeated) and how best to adapt to situations to become the best version of myself.

Survival priorities

A large part of my longevity in the battle to defy CF is credited to the amount of sport I played throughout my life, whether it be football, hockey, basketball, running or weight training in the gym. Regular exercise is a necessity for keeping my lungs tuned – it is one of my treatments.

Also important to me is opening up with CF friends over the phone, and keeping a blog. Blogging is very cathartic and stops the build-up of harmful supressed emotions. I'd recommend it for everyone, even if you're the only one that sees it.

I have also learned that the resilience shown by surviving CF is an asset in the workplace; it's life-changing and positively wipes out the silly things I observe others wasting valuable time on!

Biggest motivation

As a young adult, I remember standing with my mum on the pier in Weston-Super-Mare and telling her I didn't think I'd find a suitable partner and ever have children. But, I learned to quickly tell which girls didn't 'get' CF, and which could cope with the sights and sounds of the condition. My wife and I bore the emotional rollercoaster of IVF to bring our miracle child into our lives and my family provides me with extra motivation to keep battling and stay as healthy as possible.

Everyday mindset

I aim to be my own CF champion by re-setting myself mentally at the start of every day and telling myself what I will do and achieve that day despite my condition. It's important for people with CF to reward themselves and celebrate our determination and bravery to endure every day what is not yet cured."

Find out what survival lessons Tim would give his 20-something self, at cysticfibrosis.org.uk/timstips

Tim with wife Katie and and son Felix

Ready for action

"It's important for people with CF to reward themselves and celebrate our determination and bravery." – Tim

Stopping the clock

You may have seen us talking about stopping the clock on cystic fibrosis – perhaps you are among the thousands who have signed a petition, shared your story and even watched our recent parliamentary debate (more on that below!).

But what does it mean?

Stopping the clock on cystic fibrosis is about helping deliver faster access to better treatments. We are working at every stage of the drug development journey, from supporting cutting-edge research to participation in clinical trials to fighting for newly licensed treatments to be made available, for free, to everyone who could benefit from them.

Where do you come in?

When you give your time, your money and your voice, you can bring us closer to stopping the clock on cystic fibrosis and our ultimate goal of a life unlimited for everyone affected by it.

In the last issue of CF Life we offered the chance to get involved in trials and research by providing a voice from the community. People with CF and their families, friends or carers have been helping shape our resources and have been sharing their experiences of clinical trials or their understanding of the trials process. They have also given their views on our planned Trials Database, and many have expressed an interest in joining our Advisory Group. With training, the group will be able to support the CF Community considering taking part in a trial and promote the value of research.

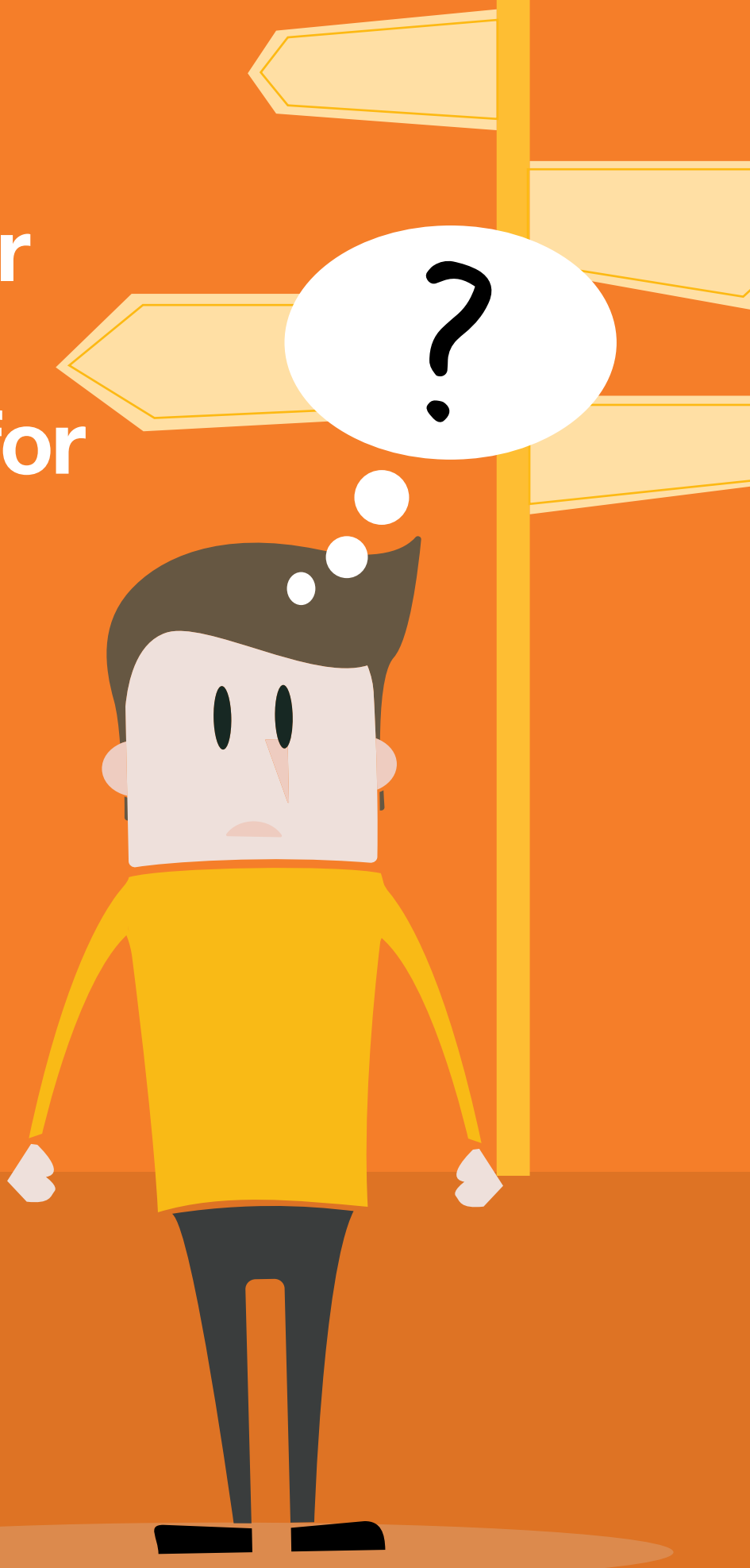
Getting heard in Parliament

At the end of 2016 we held a parliamentary debate with the support of MPs Ian Austin, Kerry McCarthy and Ben Howlett. The debate aimed to put pressure on the Government to be more flexible in their approach to the negotiations around Orkambi, as recommended in a recent report.

Darren O'Keefe, Public Affairs Manager at the Trust said: "I was delighted by the passion and support from MPs across the party divide who came together to share stories from our community, which made a compelling argument for speeding up access to drugs like Orkambi. As a result of the debate the Trust has been able to meet with the Government to discuss a way forward."

And of course, every penny you donate or raise will support our fight for a life unlimited by cystic fibrosis.

Hoping for the best, planning for the worst



Living with cystic fibrosis (CF) can mean being more aware of issues like life expectancy, but that doesn't make them any easier to talk about.

Dr Ruth Keogh at the London School of Hygiene and Tropical Medicine has been looking to understand how people with CF feel about finding out about their life expectancy and other outcomes. This research, funded by the Medical Research Council, explores how different measures impact on survival in CF, and works towards providing individualised predictions.

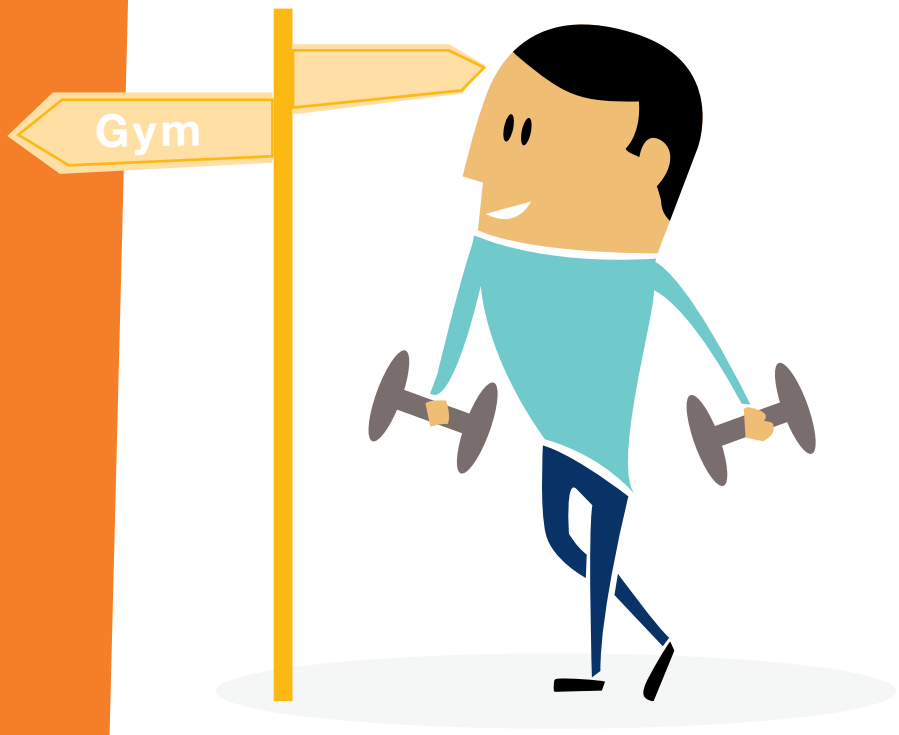
What do people want to know?

Ruth says: "My survey asked 85 people with CF what they wanted to know about life expectancy and other health outcomes. Many of them had sought information on this topic, especially from online sources, but less so from their CF teams. The Cystic Fibrosis Trust website was one of the main resources for this type of information. The tendency to look online could be because it's easier to read this sort of information alone than it is to discuss it with people who know and care about you."

When it came to life expectancy, Ruth found that most would like to know more, sooner or later: "Most people who hadn't asked for this type of information said they would probably like to have it in future, and many of those that had said it helped them plan their lives – managing their health and psychological aspects of their condition, as well as informing decisions around careers, leisure time, families etc. When the time comes, CF teams are well trained in having these discussions."

"At the time she was about to go on the transplant list, but was very aware of the seriousness of that and although was hoping for the best, was also preparing for the worst."

– Alasdair Mackenzie



"When I was 16 I began to question what the average life expectancy was for someone with CF and was shocked to discover that it was just 30 years old. This realisation was to become a turning point for me and how I was to tackle this terrible disease. I then joined the gym and started to train. I never looked back from then."

– Gary Bramhall

Taking the plunge

While it's a tricky topic to navigate, discussing your end-of-life plans with your CF team and loved ones can help lighten the load at a difficult time. Whether you have CF or not, practical steps like planning your funeral and writing a Will don't have to wait until your health declines and may even be easier to tackle when you're relatively well.

Alasdair Mackenzie and his wife Becky, who had CF, made their plans for the future together. "Becky and I made Wills several months before she died," he says, "and I know she also spoke with her priest about possible funeral arrangements. I think Becky wanted to make all the essential practical preparations so that she could focus on enjoying her life, because she just didn't know how much time she had left.

"At the time she was about to go on the transplant list, but was very aware of the seriousness of that and although hoping for the best, was also preparing for the worst."

By putting pen to paper and making your wishes clear, you can make sure they will be respected in future, and get back to focussing on the here and now.

If you are affected by any of the issues in this article, you can call our helpline on **0300 373 1000** or visit **cysticfibrosis.org.uk/planningahead**.

"I think Becky wanted to make all the essential practical preparations so that she could focus on enjoying her life, because she just didn't know how much time she had left."

– Alasdair Mackenzie

Will-writing

While we can't provide you with legal advice, our Gifts in Wills team can discuss the will-writing process with you and provide an planning document to allow you to start considering who you would want to benefit from your estate. You can also register for our Free Wills service during September, allowing you – or you and a partner – to have a simple Will prepared by a local participating solicitor free of charge.
cysticfibrosis.org.uk/freewills

Planning ahead

If you're ready to take the plunge and start thinking about planning things like your funeral and your Will, we have plenty of information ready and waiting for you at **cysticfibrosis.org.uk/planningahead**.

Helping us help you

"We feel that by helping out, we have assisted with passing on the Trust's messages. Spreading a working knowledge of CF has certainly helped Arthur lead a perfectly ordinary school life, with little or no disruption."
- David and Cat Elliot, who took part in creating our primary school pack and featured in the film.

Tracy, Mike and twin boys Baden and Jamie featured in our fertility information pack.

Grace and parents Jen and Geoff featured in our new primary school information pack.

The only reason we're able to offer such a wide variety of information resources to support families affected by CF is because of you!

We work closely with people across the CF community to develop new information resources, getting out and speaking to as many of you as we can to get your views and experiences to inform our publications and films. The contributions from individuals and families affected by CF have been absolutely invaluable. Here's an example of how it goes…

The helpline team tells us that lots of people enquire about managing the move to pre-school or primary school and they want to make sure they have the best information available to give them when they do.

Our first port of call is you. Through social media and CF centres, we make contact with parents, clinic staff and teachers to discover what information we should cover: infection control, Creon®, treatment burden, school trips and absence; and share their top tips on what was easy or challenging about starting school. You also help us find the right format: in this case parents and professionals suggested a booklet for parents, leaflets for schools and a film.

Using these views and experiences, we then start the writing, photography, design and filming needed to create our primary and pre-school information packs.

Before launching, the information pack is sent to our Clinical Advisory Group (CAG) – a specialist group of CF professionals and community representatives – to check it's accurate.

Hopefully you have found our publications or films useful. There are more on the way – our secondary schools pack launched in March 2017 and will be followed by information on going to college/university and resources looking at transplantation. If you'd like to help with developing information, we'd love to hear from you at enquiries@cysticfibrosis.org.uk.

Yoga – something for everyone

Exercise doesn't have to mean a 'Rocky' training montage or a quest for Olympic gold – it can be a gentle way to improve your health and wellbeing.

Katie Malik is a yoga instructor who draws on her experience living with cystic fibrosis. Working with online fitness specialist Pactster and the Cystic Fibrosis Trust, Katie has helped produce a series of exercise videos tailored to people with cystic fibrosis.

"I first discovered yoga about six years ago when I was having a decline in lung function and I decided that I wanted to try and get that lung function back after I went on some antibiotics and they didn't boost me up quite as much as they should have.

"I went to every single kind of class that I could find at my local gym just to see what I liked and what I would stick with. Yoga ended up being a thing that I just kept going back to, and I enjoyed that gradual growth, being able to see that I could do something that I couldn't do before."

1

Mountain pose

This is the foundation to all standing yoga poses and will help to improve your posture.

2

Warrior 1

A great pose for strengthening your legs and core, improving your balance, and opening across your chest. Remember to breathe!

3

Cobra

This back bend will help to stretch out your chest, abdominals and shoulders, and reduce stiffness in your spine.

"We hear all the time from our doctors that exercise is good for us, but without an inherent motivation that comes from inside ourselves it can be hard to stick with it. I think it's important to find the thing that you're passionate about so your motivation comes from within."

– **Katie Malik,** yoga instructor


Katie Malik

After standing in for instructors on a few sessions, Katie found she had a gift for teaching yoga.

"I had something unique to offer the yoga community because so much of my experience had been informed by my CF and dealing with a chronic condition.

"At the same time, I have this unique knowledge that I can bring the CF community because I have seen first-hand the benefits of yoga and how it's improved my daily life. I take a multi-level approach because there's such a diverse range of abilities, stamina and strength within the CF community."

Katie is the first to acknowledge that it can be hard to keep motivated, particularly for people with CF, who can struggle with fitness levels.

"We hear all the time from our doctors that exercise is good for us, but without an inherent motivation that comes from inside ourselves it can be hard to stick with it. I think it's important to find the thing that you're passionate about so your motivation comes from within.

"Maybe it's going to be yoga, maybe it's going to be running – find the thing that you enjoy doing and it will be so much easier to make that a part of your regular routine."

Don't forget to consult your CF team before attempting to do any of the exercises.

You can find Katie's yoga videos along with a variety of other instructors at Pactster.com.

Pactster aims to support people with CF to exercise more by offering on-demand exercise sessions led by CF fitness role models and physiotherapists. You can track how much exercise you have done, and workout with others via video-chat - a fun way to overcome cross-infection issues!

Use promocode CF-TRUST for six months' free access.

Hello from hospital!

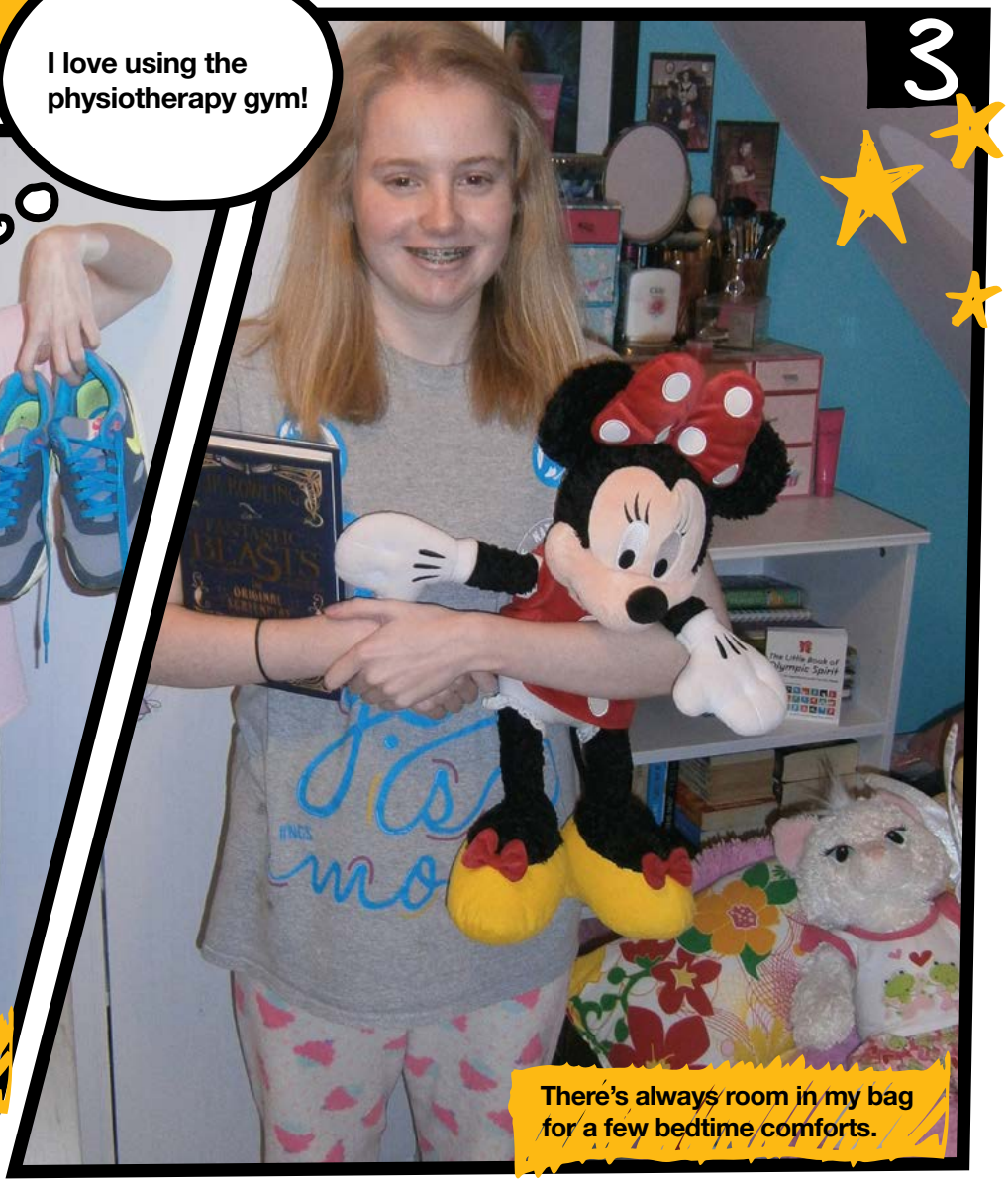
Siobhan is an 18-year-old vlogger, and this year she transitioned from paediatric to adult care.

Here she let's us in on what a typical hospital admission is like for her.

Let's get packing! I've got lots of books and movies to keep me entertained.

Choosing some comfy exercise clothes.

I love using the physiotherapy gym!



There's always room in my bag for a few bedtime comforts.

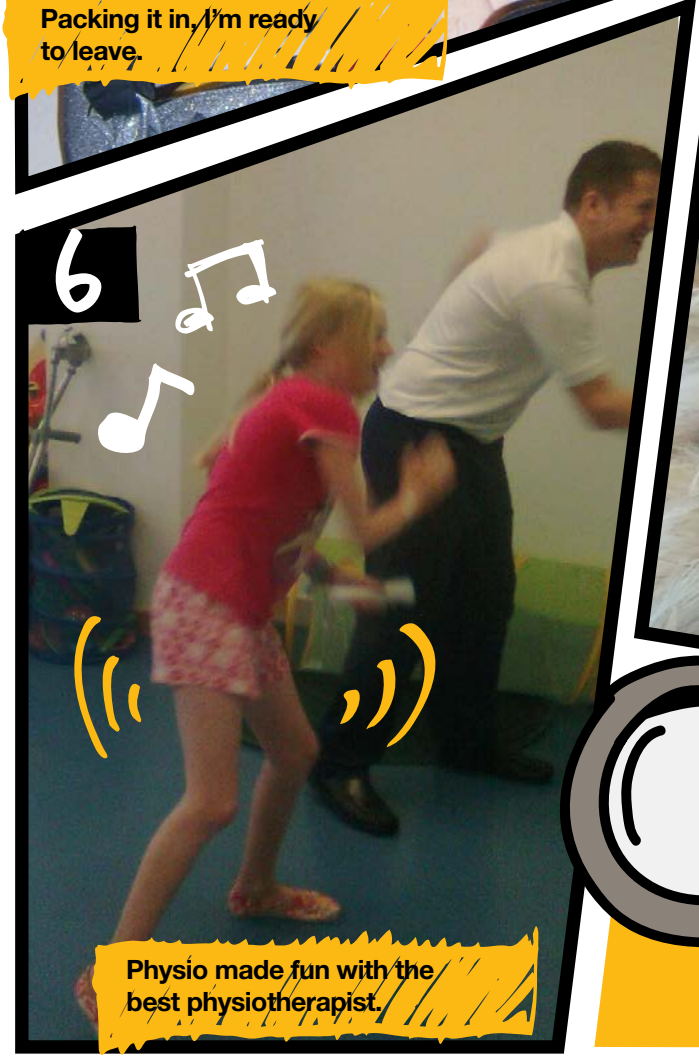
4

Packing it in, I'm ready to leave.

Smile, hospital isn't all bad!

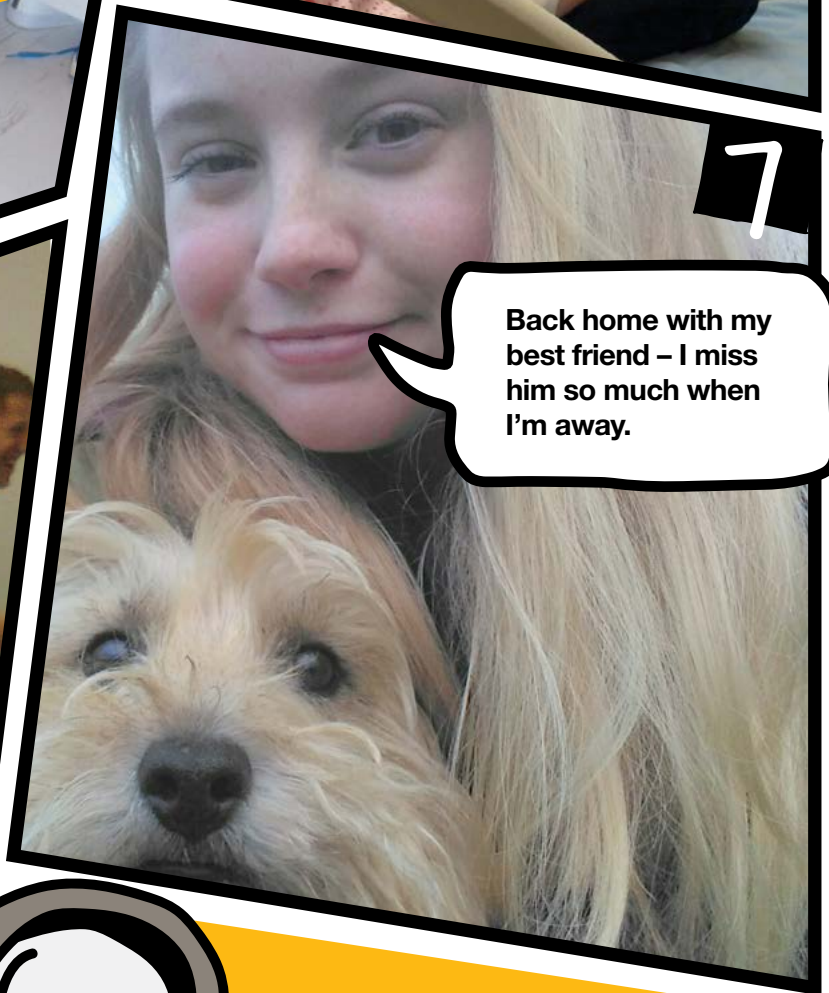
5

6



Physio made fun with the best physiotherapist.

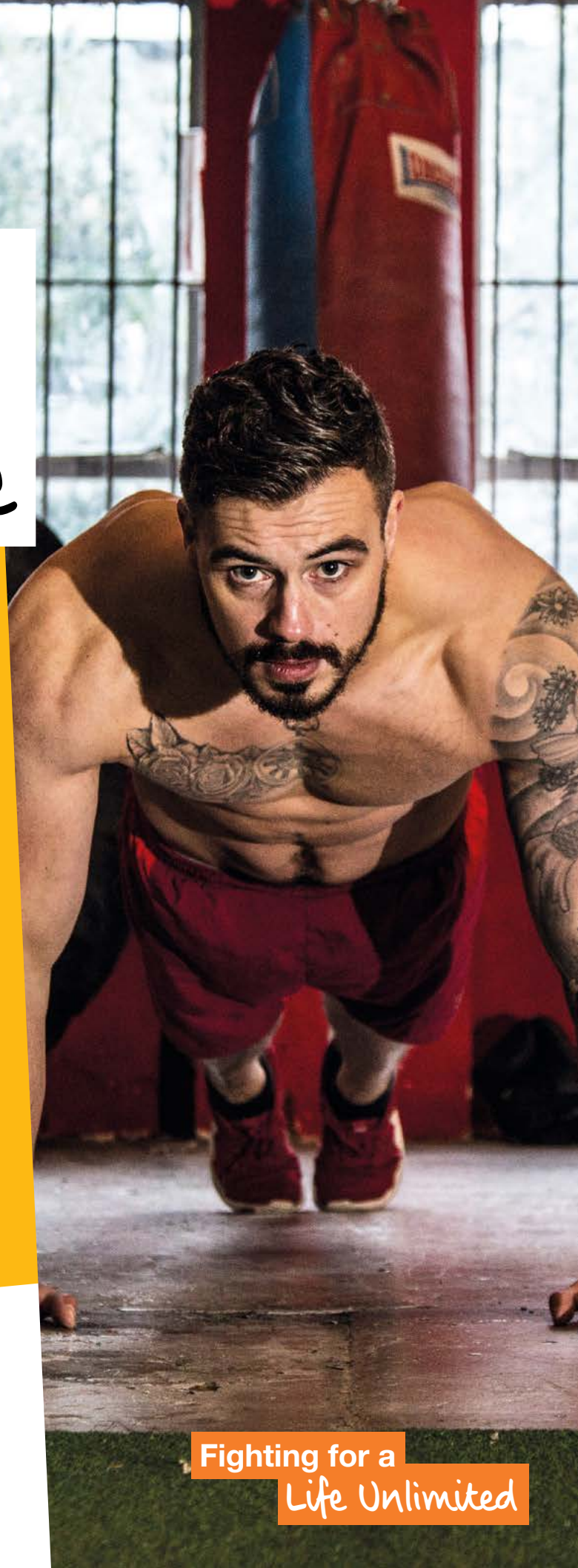
7



Back home with my best friend – I miss him so much when I'm away.

See more of Siobhan's world on her YouTube vlog – search 'Colezy's Corner'

Cystic Fibrosis a lifelong challenge



Reaching a milestone birthday is often a cause for an extra special celebration and for Josh Llewellyn-Jones, who has cystic fibrosis, his thirtieth birthday is no exception! He is using his big day to take on an epic fundraiser for the Trust: a 24-hour fitness challenge.

On 29 July, Josh will attempt to lift 100 tonnes, cycle 100 miles, run 10 miles, row 10 miles, cross train 10 miles, swim two miles, and do 3,000 sit-ups, enduring 1,000 press-ups and crushing 1,000 squats!

It may not be how you fancy spending your birthday, but keep your eyes peeled for your opportunity to join Josh virtually in his challenge.

www.24hrs4cf.com

Fighting for a Life Unlimited