cysticfibrosis.org.uk

CF Life

Issue 1

IT'S ALL ABOUT YOU!

Your new-look magazine, bringing fresh perspectives in the world of cystic fibrosis

Focus
This time it's personal

Coughy Break
Find our new feature inside!

Lifestyle
Healthy hobbies & easy exercise

Fighting for a Life Unlimited

Cystic Fibrosis Trust

What's inside

Issue 1 – September 2016

REGULARS

REGULARS

LIFESTYLE

FEATURES

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All communications should be sent to:

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

magazine@cysticfibrosis.org.uk

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Welcome to CF Life

In the three years since 'is' magazine launched, the world of cystic fibrosis has changed. Precision medicine has appeared, the CF population has grown, and we are learning more each day about how cystic fibrosis works, and how it affects you.

We have changed, too. Last year we announced our new focus: fighting for a life unlimited for everyone affected by cystic fibrosis.

We've put a huge amount of energy into better serving you, our community, and thanks to your support we've continued to push the boundaries of scientific research and the future is looking brighter than ever.

As part of our new direction, we have been reaching out to get you involved in everything we do. One thing we wanted to know was what you thought of our magazine. What did you like? What didn't you like? What did you want to see in a new magazine? What should we call it? Your responses were bigger and better than we could have hoped for. See for yourself on page 4.

We also wanted you to be involved in creating the magazine itself, whether it was writing articles, interviewing specialists, or contributing artwork.

The name 'CF Life' was chosen by you, and we think it sums up what our fight for a life unlimited is all about: creating positive futures for people with CF, their friends and families.

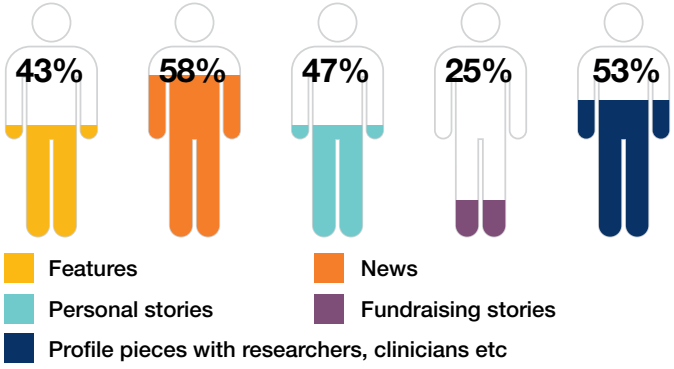
Thanks to you, we believe that the magazine is the best it's ever been, but we can always do better – get in touch at magazine@cysticfibrosis.org.uk and let us know your thoughts.

The Editorial Team

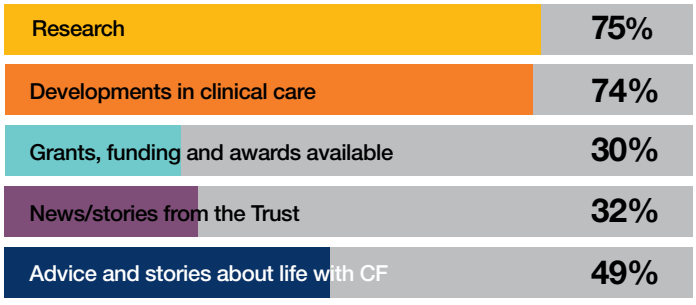
Our survey says...

Earlier this year we asked you to tell us what you wanted to see in your magazine – and even what you wanted to call it! Thank you to the hundreds of you who took part in our survey and readers' poll – here are some of the things you told us.

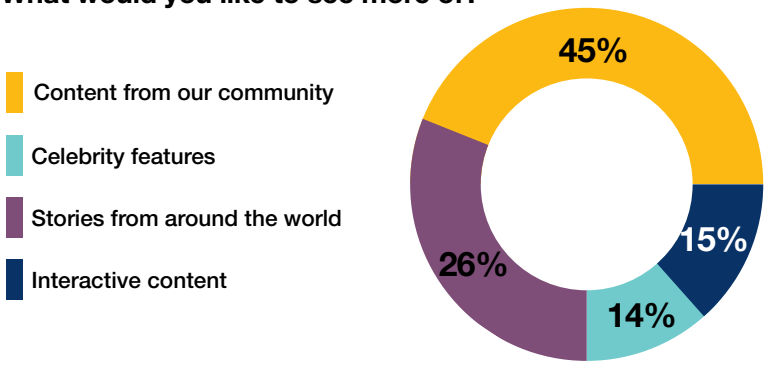
What do you like most about the magazine?



What do you most want to read about?



What would you like to see more of?



Staying in touch - your permission matters!

We need your help to turn up the volume on cystic fibrosis – but upcoming changes in the law mean you need to give us permission to keep you up-to-date with all the latest news from the Trust and the world of cystic fibrosis.

This is your opportunity to say how you'd like to be contacted. Please visit cysticfibrosis.org.uk/keepintouch and join our fight for a life unlimited.

We treat your personal information with the utmost care, and will never sell your information on. Instead we aim to contact you only about the vital work that you want to hear about, in the way you would like to hear about it.

That's why just a few ticks can now make all the difference.

News in pictures

The muddier the better

100 plucky fundraisers took on Born Survivor (where we are the charity partner this year), raising almost £80,000 and getting pretty dirty in the process!

Crossing the Atlantic for the Trust

For three months, two teams braved a handful of hurricanes and 3,400 miles to row across the Atlantic for the Trust, raising tens of thousands of pounds! We hope they brought an umbrella…

#DonateMate goes viral!

Charles Michael Duke, who is waiting for a double lung transplant, was on ITV's 'Loose Women' earlier this year encouraging people to sign up to the organ donor register with his social media campaign. After his appearance over 1,700 people signed up!

Liam's fundraising honour

Liam McHugh (pictured with his wife Eleanor) was awarded a British Empire Medal (BEM) in recognition of the 15 marathons he has run since his daughter Rachel was diagnosed with cystic fibrosis.

Piccadilly Circus took our breath away

We lit up Piccadilly Circus with our Breathe campaign!

The toughest race on Earth

Richard Atkins and Justin Turvey completed the world's hardest marathon, through scorching sands and blistering heat, raising almost £14,000 for the Trust.

Our 2016 Christmas card & gift shop is now open!

cysticfibrosis.org.uk/**cardshop**

Thank you to everyone who raised over **£23,000** last year by buying their cards and gifts with us.

Don't miss out on cards designed by the winners and runners-up of last year's children's Christmas card competition!

Visit cysticfibrosis.org.uk/cardshop for details of this year's competition and to buy your cards and gifts.

Fighting for a Life Unlimited

This time it's personal

Personalised care: a bold new world we're just starting to explore

It's an exciting time in cystic fibrosis care. People are living longer and healthier lives than ever before, the result of great progress across a range of areas. Personalised care is the next big opportunity, and we plan to grab it with both hands.

Cystic fibrosis has a thousand faces, and no two people have the same experience of the symptoms and challenges it can present, so why should their treatment and care plan be the same? We asked people to answer two questions about their relationship with cystic fibrosis (have a look at the bubbles on the right); the variety of responses highlights how each struggle against CF is unique, and how everyone has their own goals and ambitions.

The question everyone is starting to ask is: are clinicians able to adapt the range of treatments used by people with cystic fibrosis to give the best results for them as individuals? The options for monitoring symptoms, building up health and fighting off disease are largely the same. We're working on building the tools that will empower people with cystic fibrosis to create their own life unlimited. **Here's how.**

For you, what are the biggest barriers to a life unlimited by cystic fibrosis?

- Money for research
- Lack of truly effective medication
- Approval for medicines
- Time-consuming daily treatments
- Funding for drugs
- Lack of organ donors

What does a life unlimited by cystic fibrosis look like to you?

- Enjoying a normal life
- No shadow of lung transplants and premature death
- No fear of a future without my sons in it
- Being able to maintain loving relationships
- Getting a good education
- Taking care of my body
- Fulfilling my dreams

Getting to know you

Our UK CF Registry securely contains detailed health information about more than 10,000 consenting individuals fighting their own fight against cystic fibrosis. It provides a snapshot of the CF population in the UK at a given time, providing rich information for researchers and clinicians. We can use it to spot trends based on genotype, treatment, demographics and much more, and to prove the real-world, long-term effect of treatments. We've updated the platform the Registry runs on, and have big plans for a time when everyone with cystic fibrosis will be able to enter their own information to supplement the clinical data that's already there.

New technology is changing the way that we monitor healthcare

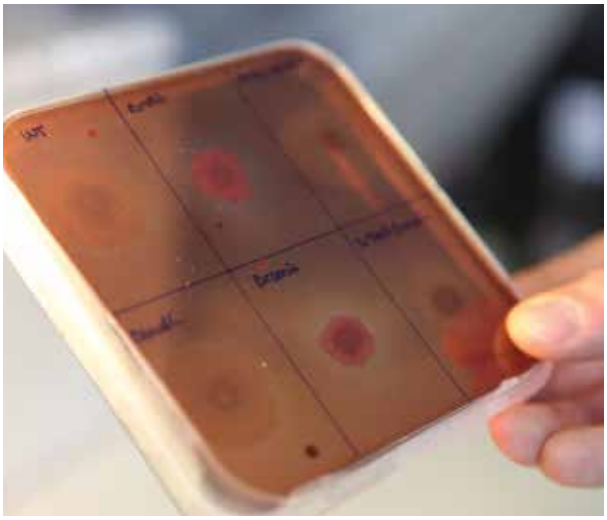
> We're pioneering new ways of working with academics, clinicians and researchers, tapping into expertise from around the world.

Doing it your way

The SmartCareCF project, currently making its way through feasibility studies, will allow people with cystic fibrosis to track data about their condition. By empowering people to take control of monitoring some aspects of their cystic fibrosis, there can be more options for treating them. The data produced will supplement the clinical data in our Registry, creating even richer resources for researchers to work with. If you want to track some of your symptoms with cutting-edge technology, we want to help you do that from the comfort of your own home, and make changes to your routine based on the results. If you want to leave all that to the experts, that's fine too; it's all about having options.

All together now

We're pioneering new ways of working with academics, clinicians and researchers, tapping into expertise from around the world. Our Strategic Research Centres, and soon our Innovation Hubs too, are a lively network of expertise, information sharing and collaboration. We are taking the big issues in CF and getting the best minds to think about how to fix them for every single person with the condition, not just the majority. And some of those challenges aren't unique to CF – our hubs will help us bring in resources available to more mainstream areas of research so we can get in with the big hitters.



Test and learn

Of course, clinical trials are the battleground where new treatments prove their worth. They're expensive, complicated and require numerous participants. There are many hurdles to jump, and our Clinical Trials Accelerator Platform (see page 21) will help us jump them more efficiently than ever before, powered by UK CF Registry data. By improving information around clinical trials and creating a network of clinical trial centres, we'll build a better research environment and pave the way for trials to happen more quickly. We're shooting for the day when everyone will know as soon as a new trial they can take part in opens.

The long game

By better understanding everyone who has cystic fibrosis and what matters to them, we can build new paths toward brighter futures. The progress made so far provides a great foundation for the exciting work starting all around us, but it will take time – and the help of the tight-knit CF community. A more informed and empowered community is going to be the driving force behind this project, and we'll be there every step of the way.

So whether you want to invest all of your data, take part in a clinical trial and measure some of your own symptoms, or you like things exactly as they are, we know you'll be watching this space. We're building the tools that will help you create a life unlimited by cystic fibrosis.

By better understanding everyone who has cystic fibrosis and what matters to them, we can build new paths toward brighter futures.

It's not just lungs...

Research into lung treatments is vital, but for people living with cystic fibrosis everyday life is often about more than just healthy lungs. Everything from encouraging young people to stay active, and harnessing vital data to improve lives, to freedom from additional complications like joint pain and diabetes. With this research, we hope the cystic fibrosis community will be able to make the most of all the opportunities life can offer.

Some of our new (non-lung!) Strategic Research Centres…

Exercise

The science

1. Exercise has been proven to have a positive impact on lung function, as well as having many psychological health benefits.
2. Teenagers and young adults living with CF are the most likely to neglect their exercise regimes.
3. Low levels of activity are linked to a decline in lung function.

The plan

Over three years, this research centre will investigate the effect physical activity has on young people, and will look at the links between exercise, hospital admission rates, and school and employment attendance.

As part of the project, the team will produce a brand new online programme called ActivOnline to promote physical activity.

Joint pain

The science

1. Arthropathy (joint disease) is one of the fastest growing complications for people living with cystic fibrosis.
2. Joint pain affects more than 1 in 10 individuals with cystic fibrosis.
3. The condition can seriously impact mobility and quality of life.

The plan

This centre will focus on delivering ground-breaking research into cystic fibrosis-related arthropathy (CFA). Researchers will develop a specific classification of CFA, research therapeutic treatments, and investigate the role of ultrasound in identifying joint inflammation.

The study will also investigate the link between joint inflammation and inflammation of the lungs in people with cystic fibrosis, to find out whether the two conditions are linked, and the relevance this could have for potential treatments.

50%
of adults living with CF have diabetes.

Diabetes

The science

1. The defective CFTR gene increases blood sugar levels.
2. Around 50% of adults living with CF have diabetes.
3. Preventing the development of cystic fibrosis-related diabetes (CFRD) could increase life expectancy.

The plan

This brand new centre will investigate how the defective CFTR gene increases blood sugar levels and causes CFRD. Specialists in diabetes and cystic fibrosis research from Europe and the USA will work together to try and discover ways to prevent the development of CFRD, increasing life expectancy and helping people with CF to live a life unlimited.

Data

The science

1. Current data systems used by the NHS do not communicate effectively with each other.
2. This makes it difficult for useful information to be used productively.
3. The NHS is moving towards 'big data', a way of using data systems that will ensure information is harnessed effectively.

The plan

This virtual research centre will be instrumental in making the CF community leaders in NHS 'big data'. The team will link the UK Cystic Fibrosis Registry with other health and educational data, helping medical organisations identify treatments that are beneficial to the health and life quality of people living with cystic fibrosis.

This information will also help clinicians to understand the impact CF has on education and employment while exploring why patients from poorer families experience more health problems.

Find out more at cysticfibrosis.org.uk/SRC

Meet... Stephen Hart

Above: Prof. Stephen Hart
Below: Leanne with daughter Anna

"Meeting patients, families and carers, I could see how much passion there was for our research; their hope has stayed with me throughout my career, and continues to inspire me today."

- Professor Stephen Hart

Leanne, from Scotland, is the mother of three beautiful girls. One of her daughters, Anna, has cystic fibrosis.

We gave Leanne the opportunity to ask Professor Stephen Hart, the Principal Investigator on our Gene Editing Strategic Research Centre, a few questions about his research and what it could mean for her daughter and others like her.

What got you interested in cystic fibrosis research in the first place?

After I got my PhD, I took a research position in one of the first gene therapy projects in the UK. This project was investigating cystic fibrosis. The CF gene had just been discovered, so we were well positioned to start developing a gene therapy. I was excited, but I knew very little about cystic fibrosis. I started engaging with the CF community and charities like the Cystic Fibrosis Trust, and this brought the project to life for me. Meeting patients, families and carers, I could see how much passion there was for our research; their hope has stayed with me throughout my career, and continues to inspire me today.

I'm still new to the world of cystic fibrosis; how would you explain gene editing to me?

CF is caused by a faulty gene. In this gene, the order of the DNA is incorrect. With gene editing we are trying to fix the individual's CF gene by repairing the order of the DNA.

Will the treatments you are working on be specific to each mutation, or will they work for every person with CF?

We are working on a mutation-specific approach and one that will be applicable to all patients, and it is difficult to predict which approach will be best at this stage. Initially, we are focussing on the most common mutation, but in principle the same technique could be applied to all mutations.

What would be the greatest outcome for your research?

From this project we hope to understand how to use and deliver gene editing to develop therapies for all patients. If all goes well, we hope it could lead to the development of a number of new treatments.

How have medical advances impacted your research over the years?

Our project would not be possible without the enormous advances we've seen in genetic research. Developments in DNA sequencing, basic understanding of the CFTR protein, and ground-breaking gene-editing systems have all had an incredible impact on my research.

The media tends to present medical advances as sudden breakthroughs, but drugs like the precision medicine Kalydeco are often the result of years of research by scientists around the world. These breakthroughs wouldn't be possible without funding from the Trust and other charities and government organisations. Their continued support has been indispensable.

At the moment you are working out how to deliver gene-editing molecules into the lungs safely. What's next?

If our treatment is effective in our laboratory studies that would be tremendously exciting and the next step would be to determine how best to translate these findings into treatments.

Find out more at cysticifbrosis.org.uk/SRChart

Siblings and CF

Cystic fibrosis doesn't just affect those born with the condition. Parents, siblings, family, friends… they all learn to live with CF, and they're all fighting for a life unlimited by CF as well. 20-year-old Imogen shares her experiences of growing up in the shadow of cystic fibrosis, and how she and her brother share a bond that won't break.

As a child, I did everything I could to avoid cystic fibrosis. If it was being discussed I'd leave the room, if it was written somewhere I'd cover it up so I didn't have to see it. Cystic fibrosis was the invisible and unpronounceable 'thing' that made my brother poorly, and I wanted no part of it.

As I got older I came to understand CF more, but that never made it easier. I was, and am, fortunate that Daniel and I have always been close: we share a sense of humour and an approach to life that unites us. However, I always struggled with the presence of an illness which could, apparently at whim, both hospitalise him and leave me feeling alone and frightened. I felt invisible when family friends greeted me by asking after my brother. I didn't feel able to be angry that CF was in my life as well as his and that, put simply, sometimes it sucked.

So whenever chest infections or awful bugs arrived, I'd bury my head in the proverbial sand and pretend it didn't exist until the brother I recognised was returned to me by a wonderful team of doctors and nurses.

Now 20, I am finally getting to grips with CF's presence in our lives. Yes, it is still hard when he is particularly unwell. But CF isn't going anywhere, so we may as well have a laugh along the way. My brother is the most resilient, witty, and determined person I know, and I love him for it. Our mum always said how lucky Daniel and I were to have each other, and our dad says if you can face a hard situation with humour, then you've won. So together – me and my brother versus cystic fibrosis? I'd say we're winning.

Daniel and Imogen: winning against cystic fibrosis

"Yes, it is still hard when he is particularly unwell. But CF isn't going anywhere, so we may as well have a laugh along the way." - Imogen

How to become a fundraising superstar!

As she approached her 50th birthday, Lorraine Barnes made it her mission to complete 50 fundraising challenges, and raise £50,000 in the process. She smashed her target, raising a whopping £51,800 for the Trust. Both of Lorraine's sons, Joe aged 13, and Dan aged 21, live with cystic fibrosis, and she is supporting the fight against CF so that her sons will see 50 years old and far beyond.

The last two events in Lorraine's incredible fundraising year were wing walking, which involved being strapped to the top of an aeroplane (rather you than us, Lorraine!) and a 50th Birthday Ball, which alone raised over £6,000. 'Coronation Street' star Tristan Gemmill attended as Lorraine's special guest for the evening, and she said she would love to go back and do the whole event again!

Over the years, Lorraine has raised a simply astonishing total of well over £300,000 for the Trust, and she is a huge inspiration to us.

Lorraine's top tips!

How do you come up with all of your fundraising ideas?

I get a lot of my inspiration for my fundraising creations in gift shops! Most people can afford to spend a couple of pounds on wristbands or keyrings, and they're ideal to bring out at fundraising events.

What keeps you going through the scarier challenges?

I just have to picture the smiling faces of all the friends I've lost to CF, or all the times I've kissed my sons before they were taken into surgery, and it doesn't seem so scary. When things get tough, I can tell myself it's all temporary. It's just a minute of my life. For my sons, CF is a lifelong struggle.

What advice do you have for people who are finding it hard to get out and fundraise?

Everyone has something they're good at. We can't all run or climb a mountain. Find something you enjoy, whether it's knitting, baking, singing, or dancing. Then rope in family and friends to organise an event. There are thousands of ways of raising money. Find one that works for you, and don't get disheartened.

As my mum tells me when I'm feeling unsure: "Nothing ventured, nothing gained."

Lorraine is keeping her JustGiving page open for another year, and her new target is to reach £55,000 by Christmas Day!

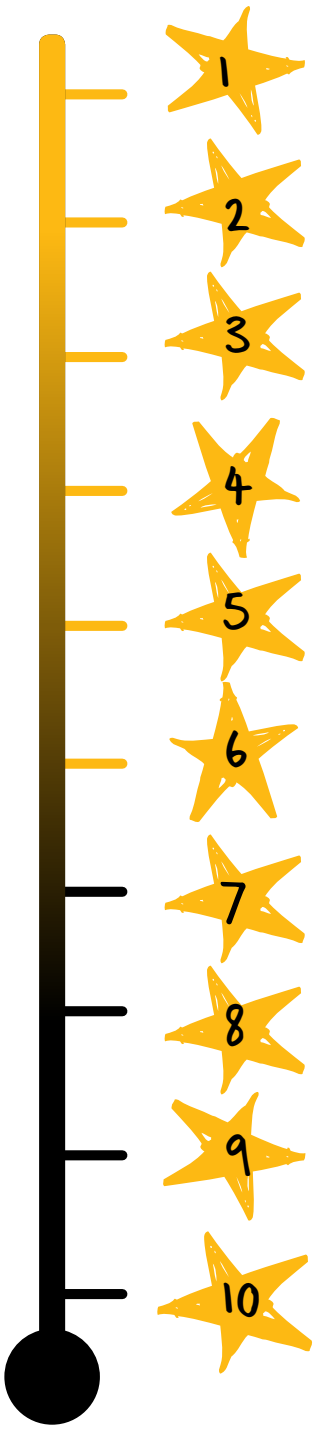
www.justgiving.com/50fundraisersForCysticFibrosis

Struggling for ideas? Here's a little help from our superstar…

If you're struggling to think of ways you can give your time to help people with CF live a life unlimited, just take a look at all the mind-boggling ways Lorraine has raised money for the Trust. We couldn't fit all 50 on this page, but you can check out the full list on Lorraine's website, **50fundraisersforcysticfibrosis.com/fundraisers.**

Here are our top ten.

Lorraine, you superstar!



1. Head Shave + £2,035
2. Abseil from the ArcelorMittal Orbit + £2,000
3. Wing Walking + £1,800
4. Tandem Bike Ride Challenge + £1,000
5. Collect 50p's for 19 months + £370
6. Unwanted Christmas Presents Sale + £258
7. O2 Arena Walk + £220
8. Eurovision 2015 Sweepstake + £195
9. Yard Sale + £150
10. Big Bounce across Humber Bridge + £120

Coughy break (thanks to Dan Goodwin for suggesting the name via Facebook!) is a new feature that shines a spotlight on the talented, creative side of the cystic fibrosis community.

Meet the glamorous artist

Poppy is a 26-year-old artist who lives in Wales with her miniature dachshund, 'Willy'. In 2015 Poppy received a double lung transplant at Harefield Hospital, and some of her most striking works deal with her time battling cystic fibrosis and life on the transplant list.

Poppy says: "I created most of the images on my website whilst I was in hospital, or at home on IVs. I was physically very weak but I was always able to paint so I focussed on that as much as I could when I had energy. I could lose myself in the detail and colour and forget about everything else. Waiting on the transplant list can be a difficult time for anyone with CF, it can be very isolating. Through my art I could create characters, or versions of myself. The Fashionista, the Misfit Poet, the Travel Blogger, the Glamorous Artist. It definitely helped me and gave me a focus. I hope I can inspire others in the same situation to do the same."

Rist (2014) (mixed media)
Digitally finished. Pen, pencil, collage, Photoshop.

"I made the headpiece of collage pieces I had collected of various organs from magazines and medical journals, and I added some patterns that looked to me like parts of lungs. At that time all I could think about was receiving a lung transplant. Again her expression is of hope, also power."

Vitamin Dreams (2013) (mixed media)
Digitally finished. Pen, watercolour, pencil, gold leaf, collage, Photoshop.

"This piece was very much a self-portrait. How I was feeling waiting on the transplant list. It is about hope. To me the flowers represent bacteria in a beautiful way. I should have called it 'Pseudomonas Blooms'."

PIG - Photography Is Good (2014)
Digitally finished.
Pencil, watercolour, collage, Photoshop.

"I was trying to learn photography for about six months. I wanted to take cool photos around the hospital. It turned out, I just CAN'T do photography. I was really mad at myself so I drew a picture instead. I think it shows freedom and independence. A girl about to live her dream as a documentary photographer."

This year Poppy was awarded a Helen Barrett Bright Ideas Award for creative entrepreneurs living with cystic fibrosis – **find out more at cysticfibrosis.org.uk/brightideas – and Poppy's work will feature in the Better Life Appeal exhibition at Waterloo Tea Gardens in Cardiff.**

There are no shortcuts to the top

By Nick Talbot

Twenty-seven years ago, I was hospitalised with three types of pneumonia. I spent my childhood going in and out of hospital, and once my health declined so severely that the doctors put me in an oxygen tent. On Friday 13 May this year (I know, unlucky for some!) I left a different kind of tent, 7,900 metres above sea level, and finished my journey to become the first person with cystic fibrosis to summit Everest. The path between has been a long and difficult one, but I was determined to see it through.

From rock bottom…

I was diagnosed with CF when I was 13 years old, after already having had some childhood health issues. The heel prick test for cystic fibrosis wasn't compulsory until 2007, so finding out your child had the condition later in life was common. By the time I was hospitalised, I was so weak that my father had to carry me out of the house in his arms. It was only then that the doctors started to dig deeper into what might be wrong with me.

When I was diagnosed, I didn't understand what it meant, and my parents chose to keep the worst possible outcomes from me until I was old enough to understand. Despite the many health complications that come with having CF, I am relatively lucky. Not only do I have a milder form of the condition, but exercise has always been a big part of my life. As a child, I spent a lot of time in the Lake District, France, and Austria, walking, climbing, and skiing. My parents encouraged me and my siblings to embrace the outdoors, and if I didn't appreciate it at the time, I realise now what a fantastic gift they gave me.

I have been climbing mountains for around 30 years, and my goal has always been to push my limits. In 2011, after two failed attempts, I climbed Cho Oyu, the sixth highest mountain in the world. I realised then that if I could do that, conquering Mount Everest wasn't such a crazy idea. But it took three attempts to reach the summit.

On my first attempt in 2014, an ice avalanche killed 16 Nepalese guides, and the route was closed. The next year, an earthquake hit Nepal, killing over 8,800 people, and triggering an avalanche on Mount Everest that killed a further 22 people. One of my team members was killed in the accident, and myself and others in my team were badly injured and had to be airlifted to safety the next day.

Nick's journey from the bottom to the top

...to the top of the world

Despite head to toe cuts and bruises, torn muscles, and a broken rib, I returned for a third attempt. I have never been as relieved as when I was able to look out across the mountains at what I had achieved. Everest had taken over my life for three years. Whether it was working on getting corporate sponsors, climbing thousands of flights of stairs in preparation, or the two months spent acclimatising and climbing from base camp, my goal had been all-consuming.

I don't know what the future holds, but whatever my next adventure is, I want to continue raising money and awareness for the Cystic Fibrosis Trust. To date I have managed to raise over £95,000 from my Everest expedition; it may just be a drop in the ocean, but I know that to a person like me with CF, that amount will make a huge difference. That thought keeps me going. This is an exciting time for people with CF, but we are still not all able to live life to its longest or fullest. If we each make our own small efforts, we can change that.

If I had any advice for young people living with CF, it would be to set yourself goals. Whether it's running a 5k or walking 100 metres, every step forward is a huge achievement. I would also encourage you to stay hopeful. Breakthroughs are happening every day thanks to clinical trials.

Over three years ago I began taking Kalydeco, and the effects have been transformative. My CF has gone from being a highly visible, intrusive part of my life, to something completely manageable.

But Kalydeco doesn't work for everyone, and I look forward to a day when everyone affected by cystic fibrosis can live a life unlimited by the condition.

Nick would like to hear from you about what he should do next. Let us know your ideas on twitter @cftrust.

Log in or sign up online to watch an exclusive Q&A Nick filmed for CF Life readers – cysticfibrosis.org.uk

"Whether it's running a 5k or walking 100 metres, every step forward is a huge achievement"

- Nick Talbot

Let's get involved in research!

Creating the right environment for research benefits everyone. Having access to the right type of research as close to you as possible not only benefits your personal care, but may also make it possible to refine treatments and care for the future.

The Cystic Fibrosis Trust has been working on an ambitious project that will bring together CF centres to accelerate clinical trials in the UK and give people with CF faster access to better treatments. The project has the impressive title of the Clinical Trial Accelerator Platform. The clue is in the title: getting clinical trials up and running quicker so that more people can become involved and benefit from research.

The track record of CF research in the UK is impressive and was recognised by the Cystic Fibrosis Foundation (CFF) in the US, which has agreed to fund the first year of accelerator activity. Essentially this funding will be used to provide accelerator platform research staff to selected CF centres, so that they can set up and deliver more research than they can at the moment.

What does this mean for you?

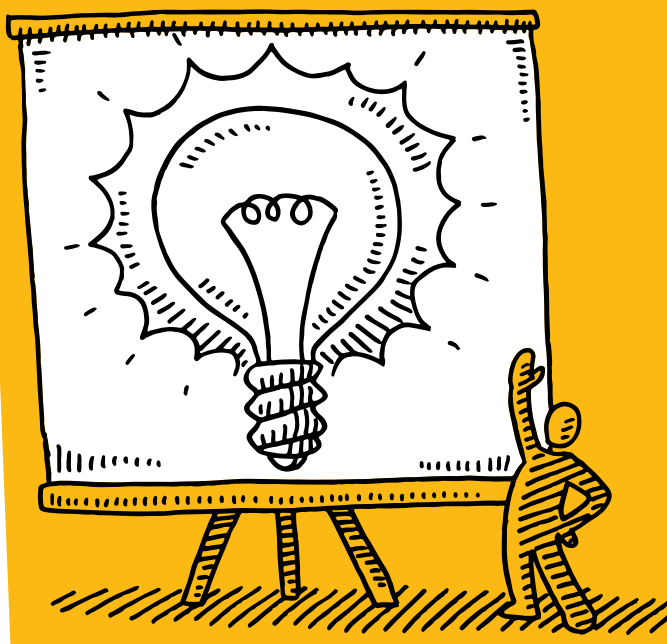
We hope that it will mean you are more likely to have a CF centre nearby that can offer you the opportunity to take part in research. These opportunities of course always depend upon you being eligible for the research.

What can you do?

Talk to your care team about research! The accelerator platform is a two-way street – we can help set the studies up but we need you to come forward and ask about research available to you.

Your potential role

Another strand of the accelerator, for those wishing to be more involved, is to train people living with or affected by CF on how to play an active part alongside the research team. Many patient groups already have people that have been trained to look at the practicality of research from a patient's perspective – are there too many visits involved? Is the research answering a question that truly concerns patients?



Get involved from the start

The accelerator platform will set up regular training for people who would like to develop their knowledge and become more involved at the beginning of a research idea. If you are interested in being part of a small group of people with CF and families affected by the condition that would provide an advisory service to researchers, please email us at involvement@cysticfibrosis.org.uk

More information about the accelerator platform can be found at: cysticfibrosis.org.uk/clinicaltrials

In the meantime – let's get involved in research!

Getting to the roots of basic fitness

No two people with CF are the same. Not everyone can run a marathon, climb a mountain or dive out of an aeroplane (just think how clogged up the flight paths would be if they could!), but no matter who you are, exercise is vital for health and happiness.

At the Llandough Hospital All Wales Adult Cystic Fibrosis Centre, Kayleigh Old has been using gardening to stay strong and healthy while she waits for a second double lung transplant.

Along with her specialist health team, Kayleigh has been turning the bare patch of grass in front of the CF centre where she and almost 300 others are staying, into a bright and colourful space. In a stroke of creative genius, Kayleigh and the team have planted flowers in old trainers, inspired by the Olympics in Rio.

"The benefits of green exercise are well worth the effort."

- **Natasha**, a CF support nurse

Staying fit and healthy can improve the chance of Kayleigh's experience post-transplant being a positive one. She said, "It's been lovely to get out of my hospital room and I have really appreciated planting, watering and watching the plants grow over the last few months. The flowers look wonderful and really cheer up the hospital site. Working on this project with my CF team has kept my muscles strong in preparation for my transplant."

The centre has been organising small-scale 'green projects' for the last three years to promote gardening as a fun form of light physical activity.

Natasha, a CF support nurse at the centre, said "Kayleigh and I enjoy coming out to the potting area to chat and see the fruits of our labour. The benefits of green exercise are well worth the effort."

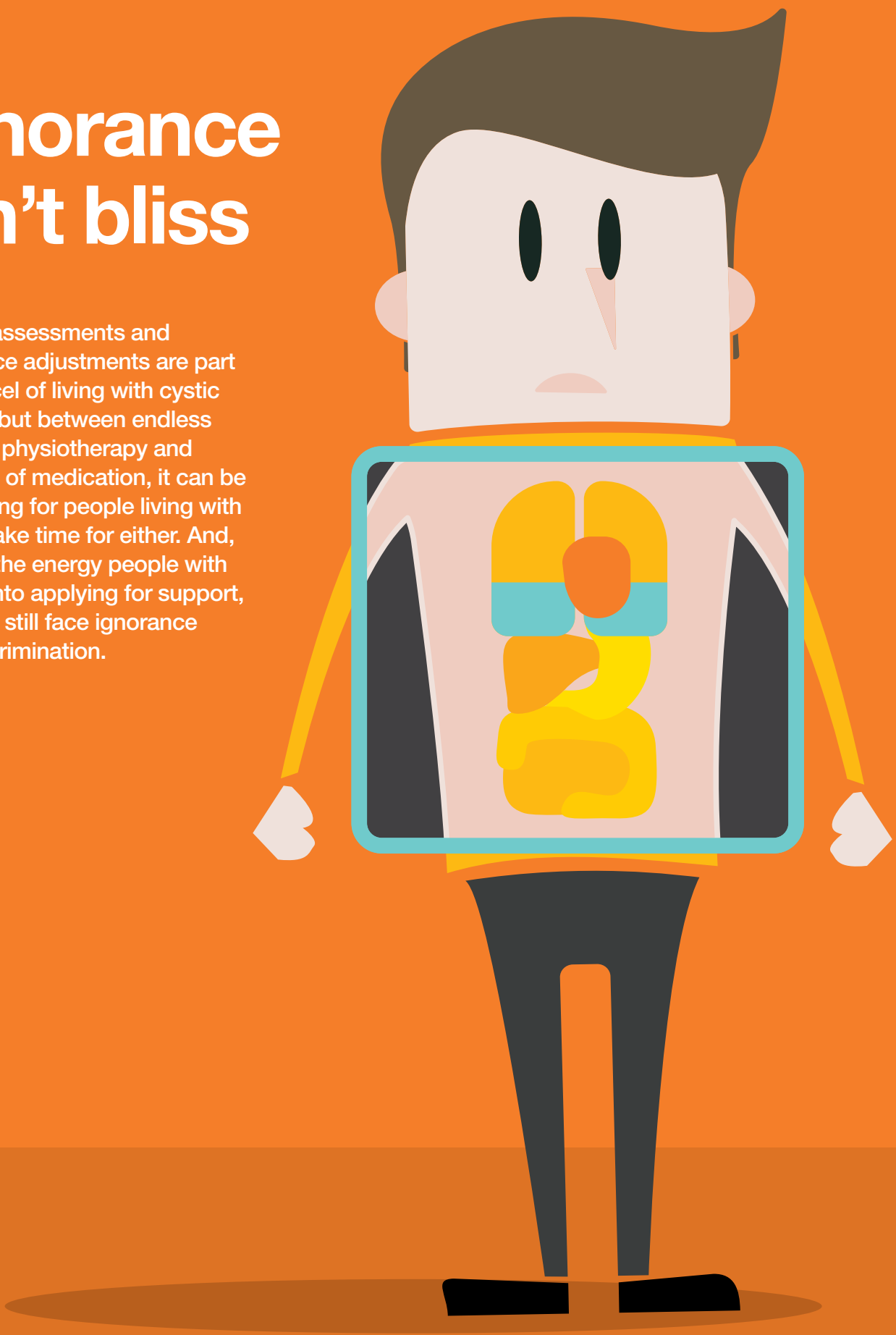
The staff at the centre know how important it is for patients to stay safe from infection while they are gardening. They recommend that people with CF use appropriate protection like masks and gloves, remain aware of the types of soils and composts being used, and make their gardening environment comfortable and safe.

Inspired by Kayleigh? Here are a few ways you can get green this autumn:

- Blackberry picking – they're juiciest at the end of September!
- Broad beans – plant now and enjoy next summer.
- Roses – red, white and even yellow, roses will brighten up any garden!

Ignorance isn't bliss

Benefit assessments and workplace adjustments are part and parcel of living with cystic fibrosis, but between endless hours of physiotherapy and handfuls of medication, it can be exhausting for people living with CF to make time for either. And, despite the energy people with CF put into applying for support, they can still face ignorance and discrimination.



But things are improving, and here at the Trust we hear stories every day of the victories people living with CF are achieving for themselves and the community. Here are three of them…

There's more to Amy than meets the eye

Amy, aged 22, had what she calls "the worst experience of my life" at a Social Security Tribunal. The second she sat down in front of the panel, the doctor appointed to Amy's case took one look at her and told her she looked "a picture of health".

The conversation turned to Amy's medication. Amy has a nebuliser, and while it is vital that she cleans it thoroughly at the end of every day so that she is not put at risk of infection, this time-consuming routine can leave her exhausted. When Amy mentioned this, the doctor asked why she couldn't put off cleaning her machine until the next day. It became clear to Amy that the doctor had little knowledge of cystic fibrosis.

When the doctor asked Amy why she wasn't doing more to help herself, she had a panic attack and had to leave the room. Since then, the tribunal has decided that Amy is entitled to PIP, and she is starting to get her life back together.

"The worst experience of my life"

- Amy, aged 22

A small victory for Carrie, a big step for CF

During a health assessment to decide on her eligibility for Personal Independence Payment (PIP), Carrie, aged 34, was asked to undertake a peak flow test. Carrie was rightfully concerned about the safety and accuracy of the test.

"I was hesitant, as the bag containing the mouth piece wasn't sealed. I wasn't sure that it was sterile, and no nose peg was provided so I didn't see how the test could be accurate."

With the help of the Cystic Fibrosis Trust, Carrie lodged a complaint questioning the safety and relevance of the test. The Department for Work and Pensions (DWP) has since decided they will no longer ask people with cystic fibrosis to perform peak flow tests, a small victory that will have a huge impact on people applying for welfare support in the future.

Carrie told us, "CF is the most common genetic disorder in the UK, and it's a crying shame how little people know about it. Scrapping the peak flow test is a brilliant result and I'm delighted that no-one else will be put at risk."

"CF is the most common genetic disorder in the UK, and it's a crying shame how little people know about it"

- Carrie, aged 34

There is no room in CF for discrimination

Philip, the former Head of English at a secondary school in York, was ousted from his job after 12 years of committed service. When Philip started teaching, his head teacher was supportive and understanding of his CF, and he was given manageable deadlines and time off for medical appointments. However, in 2013 a new head teacher was introduced who increased Philip's workload and put him under unnecessary and avoidable pressure.

"I had to cut corners in my health routines to meet huge deadlines at short notice, and my physical health suffered," says Philip.

In a shocking turn of events, Philip was suspended for a small error of judgment that an employment tribunal later ruled shouldn't have warranted more than a verbal warning. The school took Philip through seven months of disciplinary proceedings, and he was left unemployed, in poor health, with a shattered reputation.

Philip used the little energy he had left to take the school to an employment tribunal, where his former management was found guilty of "serious and substantial acts of discrimination". An upcoming hearing will decide on Philip's compensation, but now he is focussed on ensuring that this kind of discrimination doesn't happen to anyone else.

"I want employers to welcome what people with CF have to offer in the workplace, while understanding the very real challenges we face. Nobody reading this should have to go through what I did."

> "I want employers to welcome what people with CF have to offer in the workplace, while understanding the very real challenges we face."
>
> - Philip, former Head of English at a secondary school in York

Living a life unlimited

In this issue of CF Life we are focussing on making ambitions possible, and simple things like benefits and reasonable adjustments can help people with CF to live healthier, happier lives.

Amy is expecting her first baby and is close to completing a vocational qualification that will allow her greater access to employment in the future.

The DWP has reduced Carrie's PIP by over 40%, but with the support of the Trust she is appealing the decision.

Philip has a new job with a boss who respects his needs and allows him to complete his work without putting his health at risk.

If you've experienced discrimination or need support when applying for benefits, our expert Welfare and Rights Advisor is here to help. Contact our helpline on 0300 373 1000 or helpline@cysticfibrosis.org.uk

Volunteering

As a volunteer, you can play an essential part in our mission to beat cystic fibrosis for good.

CF Connect Volunteer Induction in Manchester in 2015

CF Connect

In October 2015, the Information and Support team created the CF Connect Programme, which connects parents of newly diagnosed children with trained volunteers with similar experiences. We had a great response, with 31 volunteers recruited from across the UK.

To expand the service further, our volunteers will also be supporting the community around queries with school and education. We will be providing our existing volunteers with extra training in September/ October around these issues.

In 2017 we will be looking to expand the service even further, drawing on the skills and experience of our volunteers and better supporting the needs of the CF community.

Our Philanthropy and Strategic Partnerships Team sent a "get well soon" to their Q-Project Placement Naomi Love when she was sick

Q-Project

Since November 2015, we have been partnering with Queen Mary University on the 'Q-Project'.

The Q-Project has been developed through the university career service to provide 12-week fixed term volunteer placements. These placements aim to offer relevant experience for students, and allow the Trust to enhance the work they carry out for the community.

We have developed 10 placements in our research, finance, website and media teams. Because of the high-quality placements provided, the Trust will be used as a case study for a Queen Mary University promotional video.

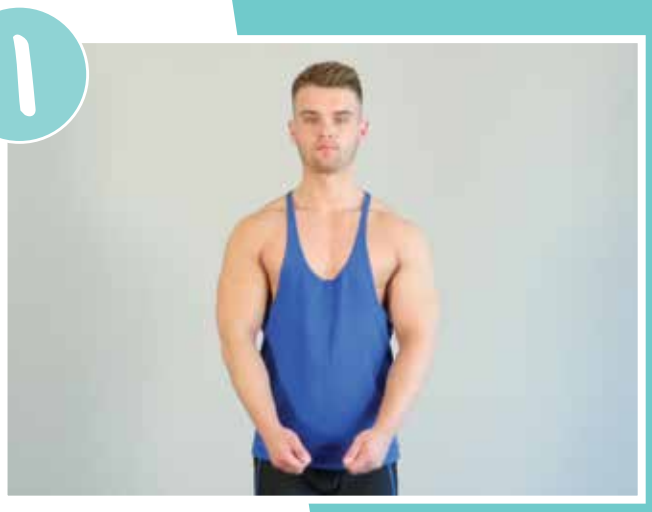
Check out cysticfibrosis.org.uk/volunteer for all the current roles – **for more information or to discuss a possible new volunteering role, contact the volunteering team on 020 3795 1551 or volunteering@cysticfibrosis.org.uk.**

Shoulder Fly!

To help everyone with cystic fibrosis try and engage in activity, helping to keep their lungs healthy for longer and maintain fitness, the Trust has launched a new online exercise programme called CF Fitness Space.

You will find a variety of simple exercises with clear, easy-to-follow instructions.

Here, physiotherapist Rebekah – clinical lead at the All Wales Adult Cystic Fibrosis Centre - and our willing model Joe Tonge, who has cystic fibrosis, guide us through the Shoulder Fly.



1 Start position

Stand with knees slightly bent, feet shoulder-width apart with your abs slightly contracted and your arms at your sides. Keep your elbows softly bent, wrists straight and palms facing down.

Brace your shoulders back to stabilise your upper-back area.

2 For the side movement

Raise your arms to just below shoulder height, and return to the start position. Try to maintain that 'W' fixed position with the arms.

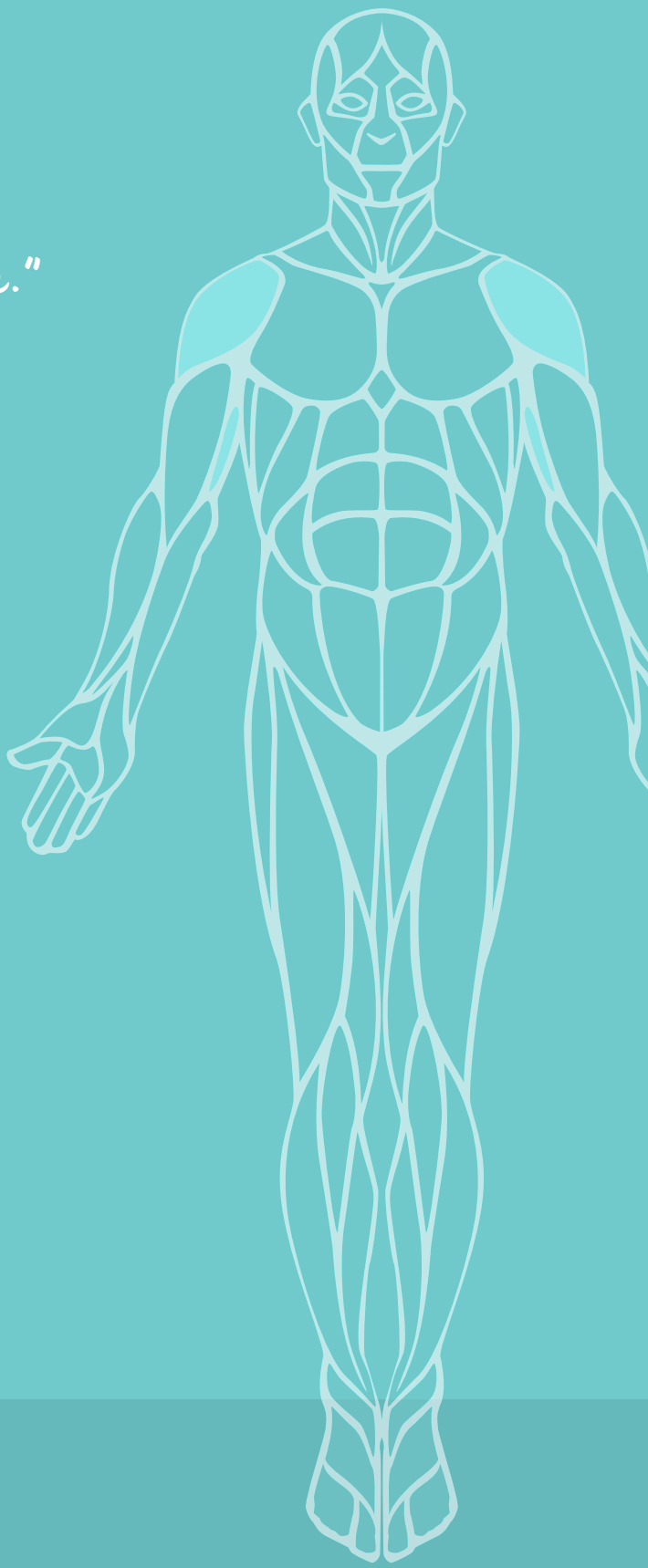
3 For the front exercise

Raise your arms, stopping at shoulder height and return to the start. And again – don't lock those elbows!

Your goal: aim to complete the exercise with perfect technique for one minute. You shouldn't feel a strain in your shoulders, but you should feel them working.

"The aim of this exercise is to work and strengthen your shoulder area and improve the endurance of the postural muscle by trying to maintain good posture during the routine."

- Rebekah



Points to note

- Your technique will improve over time as it becomes more familiar to you.
- Try to coordinate a breath out with the lifting/ raising phase of the movement.
- Technique and control should be your first priority. It should take you two seconds to raise and three seconds to lower your arms.
- Keep your muscle under tension by trying to avoid resting at the starting position.

Alternatives

- This can be undertaken as a single arm exercise and repeated with the other.
- This can also be undertaken in a seated position.

Progressions

- Slow each individual movement down.
- Increase the duration of the exercise by 15 seconds or longer.
- Add some resistance using a Thera-band or use a suitable weight (eg a tin of beans).

Get more at cysticfibrosis.org.uk/FitnessSpace

1

My ‘taxi’ arrives half an hour after the call comes. Very excited to be getting the air ambulance.

Fighting back…

In May this year, 15-year-old Keir underwent a double lung transplant, something that many people with cystic fibrosis will require at some point.

Here, Keir presents a first-hand account of what happens once the operation’s over, and recovery begins.

2

On the way to theatre for double lung transplant.

3

Day two post-transplant - sitting up and feeling good.

4

New medications - there's not so many to take now!

5

First session on the exercise bike.

6

Still fighting cystic fibrosis.

7

First walk outdoors, a week after transplant.

8

Loving life!

So happy not to need an oxygen bottle on this walk. No wheezing or coughing fits – it's miraculous.

cysticfibrosis.org.uk/freewills

Cystic Fibrosis worth a minute of your time

Don't miss out!

Pass on your legend and leave a gift in your will to help us to continue fighting for a life unlimited by cystic fibrosis.

This September we are offering our supporters a free will-writing service. You don't have to include a gift to the Trust in your will to take advantage of this fantastic offer, but we sincerely hope you will consider doing so.

For more information please contact Michael Clark by Friday 7 October on 020 3795 2132 or legacies@cysticfibrosis.org.uk

REMEMBER A CHARITY IN YOUR WILL
Help the work live on...

NATIONAL FREE WILLS NETWORK

Fighting for a Life Unlimited