

Insider

Living well with pulmonary fibrosis

Parenting with pulmonary fibrosis

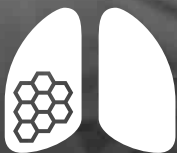
Continuing with your career

Coping with change

Being a carer and
keeping your identity

Incredible volunteers

Autumn / Winter 2023



Action for
Pulmonary
Fibrosis



2013-2023

www.actionpf.org

Welcome to Insider!

It's that time of year when Christmas plans trickle into conversation, and we're surprised how quickly it gets dark in the evening. The unique challenges of pulmonary fibrosis don't disappear when the winter festivities arrive, and we're here for you throughout it all. So, get in touch if there's anything we can help you with, whether you want a quick chat or you're looking for specific information. Whatever your experience with pulmonary fibrosis, you're not alone.

The APF Team



Recognising excellent care

A huge congratulations to Rebecca Worswick, Specialist Respiratory Nurse at Royal Bolton Hospital. Rebecca was the very deserving recipient of the Patient-Nominated Award at the ILD-IN annual conference.

"I'm truly overwhelmed. I feel very encouraged by this and so happy to hear that my work has helped so many."



What do you think about Insider?

Twice a year, Insider comes to your door (or inbox) with stories, information and news from the pulmonary fibrosis world. We'd love to know what you think about it.

If you've got five minutes, we'd really appreciate your answers to the survey you'll find on a separate insert inside this issue.

Have you got something to say or a story to tell? Feature in one of our next issues by contacting chloe.hough@actionpf.org – we can't wait to hear from you!

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2013 – 2023

Thoughts from Steve



How do we manage pulmonary fibrosis alongside all the other things in life? Well, when I was diagnosed with idiopathic pulmonary fibrosis in 2008, at the age of 59, I worked as an economic adviser abroad and travelled most of the time. I decided to keep the diagnosis to myself and carry on working. I only told my family and two close friends.

I found ways to cover up my symptoms. I took taxis and used lifts. I kept my finger hovering over the mute button on the phone in case I coughed. It worked pretty well, and if anybody commented, I just said, "Oh, I have a bit of a chest problem. Nothing serious."

In 2014, two years before my transplant, I couldn't cover it any longer. I was asked to go to Ethiopia for a month and lasted just three days. I was so breathless in Addis Ababa at an altitude of nearly 8,000 feet that I could not walk around or sleep at night. After that, I slowed down and retired in 2015.

Because I kept working, I don't think pulmonary fibrosis changed my sense of self. I was the same hard-working and family-focused bloke I had always been. When the disease really kicked in, I just changed what I did – I started relearning French, watched more TV, and prepared for our daughter's

wedding. I could also do these things as the disease progressed and I became housebound, on oxygen 24/7, and needing help showering and dressing. Finally, while being assessed for transplant in 2016, I told my friends and close work colleagues and received some wonderful support. Should I have told them earlier? I don't know.

Since I only had a single lung transplant, I will always be a bit breathless on inclines and stairs and have to pace myself. But I've discovered e-biking and do over 80 miles a week with friends, which is a great way to maintain my lung function.

As I recovered from the transplant, I decided to support people living with pulmonary fibrosis and campaign for change. I joined APF and worked just as hard as ever as a volunteer!

Despite my transplant, I still think of myself as a pulmonary fibrosis patient. I had the transplant because of the disease. Let's hope, in time, new drugs and treatments make it possible to STOP pulmonary fibrosis.

Steve Jones



Dr Mike Stubbins, our new Chair of Trustees

After six years as Chair of Trustees, Steve has decided to step down from the role in November 2023. We want to send our heartfelt thanks to Steve for his work over the years, and we're delighted that he'll be staying on as a Trustee to support the next Chair, Dr Mike Stubbins. We look forward to welcoming Mike in the next issue of Insider.

"I've got a huge amount of respect for Steve and his absolute commitment to APF and anyone affected by PF. APF has achieved great things over the past 10 years and has established an excellent team and incredibly strong foundations which we can now build on into the future. I'm really excited about what we can achieve working together over the coming years."

Dr Mike Stubbins

Continuing with pulmonary fibrosis

After being diagnosed with pulmonary fibrosis in January 2022, Simon Black, 44 from Maddiston in Scotland, made some changes so he could continue doing the things he enjoys. Simon balances a career in transport logistics, parenting a son and stepson, and avidly following Hibernian football team.



Simon with his partner, Charlotte, and son, Struan

How do you manage being a parent and living with pulmonary fibrosis?

There aren't enough hours in the day, and it's not easy, but I just have to get on with it! I think raising children is challenging regardless of whether you have pulmonary fibrosis or not.

My youngest son, Struan, and I travel to watch the football quite a lot. He's 12 so he understands that it might take me a bit longer to get to places and that I have to be careful of things like smoke effects at matches.

I think I do alright. My partner, Charlotte, is very supportive so we share responsibilities. My family are the most important thing to me, regardless of what issues I'm going through, so they come first.

Do you find it helpful to tell people about your diagnosis?

Initially, I wasn't particularly open to telling people. I had to get my head around it first and deal with it for myself and my family. I only told the people who needed to know. Now, I'm a lot more open about my diagnosis with my colleagues, and I tell them a bit about it. I think getting the information out there might just help people understand better.



Simon and his son, Struan

Is there anything that's helped you keep working?

Despite working in transport logistics, which is known for being quite old school, I'm fortunate that my employer is understanding of my condition and what I need. I want to continue working as much as possible as it's good for me and my mental health. So, I'm quick to tell my gaffer if I'm not doing that well and luckily he's very understanding.

I've registered as disabled at work, and I get support from HR and occupational health, which helps when I'm not at my best. For example, I sometimes come in later if I'm not feeling great in the morning. I'm also hoping to work from home more in the winter, as more people in the office are sick with coughs and colds which is an issue for me.

What helps you on difficult days?

The most important thing for me is to try and continue to do the things I enjoy, like going to the football. I'm just trying to do as much as I can.

I remember a mate of mine said

'The fear of death won't stop you from dying, but it might stop you from living.'

It's something that I keep with me when I go to do these things. It comes to us all so try to enjoy the best whilst you can. I also tell people, don't put anything off. If you want to go on that holiday or buy that TV, don't put it off.

Are you affected by pulmonary fibrosis?

Talk to people in a similar situation at your local support group.

Visit www.actionpf.org/information-and-support/find-a-support-group

or contact us to find your local group.

Coping with change



Whether it's becoming a parent, retiring, or moving house, everyone experiences change and transition in their life. But how do you handle this when living with pulmonary fibrosis? There's no single answer or quick fix, but we're here for you if you're juggling a lot.

We've put together a few strategies that can help people cope with change. Everyone is different, so see what works for you.

Challenge the 'what ifs'?

Do you find yourself worrying about things that may or may not happen? It's normal to think about the future but getting stuck in a spiral of negative thoughts can interfere with your daily life. Try to notice if your worry is a 'what if', and remember that it isn't a fact.

Be assertive with what you need

Do you need help around the house? More alone time? Or someone to vent to? It's okay to ask for it.

Prepare to feel uncomfortable

Sometimes you know a change is happening soon. It could be a change to your daily routine, or a family member moving away. For some people, accepting they might feel uncomfortable for a while can help them manage their feelings. If you feel prepared for the discomfort, you might be better able to cope with it when it comes.

Allow yourself to feel your feelings

Instead of trying to squash down those difficult emotions, be inquisitive about why you feel that way and consider what you need now. Try different ways to manage your emotions, whether it's talking through it with someone you trust, or taking up a hobby.

If you need support or advice, please call our friendly support line team on **01223 785725** or email supportline@actionpf.org.

Managing other conditions

Jane, an independent respiratory nurse consultant, talks to Insider about managing other conditions alongside pulmonary fibrosis.

"Let your interstitial lung disease (ILD) team know about anything happening to your physical or mental health. Knowing about other conditions or changes in your health can help them provide you with the best care."

For example, if you take steroids, it's important your ILD team knows if you are going through menopause. Both steroids and menopause can reduce bone density, meaning you are at higher risk of fractures.

Additionally, if you have other conditions, it can sometimes be difficult to know what your symptoms are related to. When your team know about any other conditions, it helps them to rule things in or out."



Life with PF: coping with change

Life with pulmonary fibrosis looks different for everyone. We asked people living with pulmonary fibrosis about their experiences, and they shared some of their thoughts and insights.

"Everybody has an image of what their role should be. Over the years, the image that I had in my head got torn away from me bit by bit. For example, having a full-time job, owning my own home, and having children. The life that everybody dreams of is the life I didn't get to have. Watching that be taken away is difficult, but then you kind of adapt your life into a new way of living."

I think one of the biggest things for anybody young like myself with PF, or anybody with the disease, is to let go of what was and let's work on what we have now."

Jyoti, 34, lives in Birmingham and has a diagnosis of non-specific interstitial pneumonia (NSIP).

"We deal with my illness as we've always dealt with anything in our life together. We face it head on, acknowledge the negative but then turn our focus to being positive, pragmatic and self-reliant."

Yes, it has hit us like a tonne of bricks. Yes, it has turned our life on its head. Yes, we have had to grieve for the future we had planned and the 'normal' life lost. Yes, we have dark days and fears. Yes, I hate that I have lost independence."

But....NO, they are not permitted to take up valuable time and energy that could be spent making the most of everyday."

Whether that is enjoying watching birds in the garden or managing a few days away to somewhere we love. We certainly don't have any answers or magic formula, but these are the things that keep us going"

Claire, 53, was diagnosed with idiopathic pulmonary fibrosis in 2021. She lives in Lancashire with her husband, Ian.

Do you have a story to share?

We want to start the conversation about managing pulmonary fibrosis at all stages of life. Share your experience with us at support@actionpf.org or call **01733 839642**.

Volunteering

Could you be our next volunteer telephone befriender?

Sophie, 30, talks to Insider about how her sister's story inspired her to become an APF telephone befriender.

"I've only been a befriender for a few months, but already it's helping me to feel connected to my sister."

After a myriad of misdiagnoses, Sophie's sister, Laura, was eventually diagnosed with pulmonary fibrosis (PF) in 2018. Three years later, Laura sadly died of the condition, at age 32.

"Laura's treatment was all over the place. She was passed to different doctors who kept repeating the same tests. We didn't feel supported, and Laura was left to manage her fear and anxiety surrounding diagnosis and death. Even her children received no bereavement support. We didn't find out about APF until after Laura died."

It now feels good to know that I am passing on bits of information that helped and comforted Laura. My sister would have benefitted so much from something like APF's befriender service, so I want to make sure others can access this service, and I know she would too."



Laura with Sophie's daughter, Phoebe



Sophie (right) with her sister, Laura (left)

What do I need to become a befriender?

- Personal experience of PF. You might have a diagnosis yourself, or be a family member, friend or carer of someone who has PF or who has died from PF. Our befrienders have PF experience in common, but they bring a huge range of different insights and approaches to befriending. **Your PF experiences could be a lifeline for someone else.**
- A minimum of an hour a week.
- Be able to listen to the experiences of others with a friendly and understanding attitude.

We're especially looking for **people who have a diagnosis of PF** to become befrienders but welcome anyone who is affected by PF, whether personally or through a loved one, to enquire.

Volunteer Spotlight: Congratulations Maureen & Maxine!

Our wonderful volunteers, Maureen and Maxine, were both at the prestigious Third Sector Awards 2023. We couldn't be prouder that they were both finalists in their categories.



Maxine (left) and Maureen (right) at the award ceremony

Maxine

Unsung Hero award

Maxine is the main carer for her husband Ron, who was diagnosed with pulmonary fibrosis (PF) in 2015 and underwent a lung transplant earlier this year. Despite this, Maxine has devoted much of her free time to supporting APF. Maxine did exceptionally well to receive 'Highly Commended' in the Unsung Hero category.

"I was honoured to be nominated for the Unsung Hero award by APF. In my eyes I just help people with this disease any way I can and certainly don't see myself in that light. Being a befriender and manning the support line is one of the most rewarding experiences I have had. To hear people's voices change and the support they feel is exactly why I do it. No one should feel alone."

Maureen

Volunteer of the Year

When Maureen's husband died of PF in 2018, she strived to help others in similar situations, despite the challenges she faced. Maureen quickly realised there was a need to provide emotional support for people affected by PF and bravely took on the challenge herself.

"Being a volunteer is so rewarding. Helping people in my support group, being an APF telephone befriender and an APF research champion gives me purpose and meaning in my life, but I never expected to be nominated for an award. I felt very humble, and it was a wonderful experience. I lost my dear husband to idiopathic PF and hope that one day, with APF's help, there will be more awareness, a better care pathway and, eventually, a treatment that can stop PF."

Thank you! We couldn't do our jobs without our wonderful volunteers, and we want to thank you.. No matter what you do, or how much you do it, every contribution is a step towards a better future for people affected by PF.

Whatever your skills and interests are, there's a volunteering opportunity for you. Take a look at apf.org/get-involved/volunteering or get in touch with our friendly team.

Remember your loved one with an APF Forever Rose – available to order now!

We're delighted to introduce a Christmas edition of our APF Forever rose – a beautifully designed memory rose, made from recycled metal, helping you remember your loved one while supporting APF.

Handmade in Cornwall, this long-stemmed metal rose is sustainable and suitable for both indoors and outdoors.

For £25 (including P&P), you can remember a loved one, and all funds raised through our Forever Roses will help fund vital support and research for the pulmonary fibrosis community.

You can also purchase our purple and white Forever Roses for £20.



To order yours, please scan the QR code or visit www.actionpf.org/fundraising/apf-forever-rose



We aim to deliver your rose(s) by Royal Mail to your door within 21 days of order. Any extension to that, due to circumstances beyond our control, will be advised.

Dee and Roger's story



Thank you to Dee for sharing her story with Insider. Dee's husband, Roger, died from pulmonary fibrosis last year. When he was diagnosed in 2016, both Dee and Roger were none-the-wiser and were left thinking it wasn't anything serious.

'All we were told was that it was scarring of the lungs.' Dee said, talking of Roger's diagnosis. *'So that's what I googled... And we came across APF.'*

Only after finding APF did they learn more about the progressive nature of pulmonary fibrosis and the support available from APF.

'I truly don't know what we would have done without APF. I used the

support line, and that was crucial for me. I also joined APF's team of telephone befrienders. I think befriending is a lifeline for people.'

Eighteen months after Roger's death, Dee talks about where she is now.

'It felt like part of me had died with him. Without him, I just felt so lost. The first year was really tough, but now I do feel like I am experiencing more joy. Grief is a journey.'



Scan the QR code to watch Dee's story.

Your donations will help us continue to be there for people like Dee and Roger at every step of the journey. Donate £5 today by texting **ACTIONPF** to **70480** or donate online at www.actionpf.org/get-involved/donate

Campaigning

The Prime Minister hears your voice



Carol Fielding, 67, from Bolton, spent her working life improving services for her patients as a specialist nurse. When she was diagnosed with pulmonary fibrosis in 2018, Carol was determined to develop these services, too.

"I sought out my local support group, which was the best move I made and where I gained most of my information. However, the more I learned, the angrier I became at the lack of treatment options. At the time, people like me, with a known cause of pulmonary fibrosis such as rheumatoid arthritis, didn't meet the criteria for antifibrotic treatment. I had come to terms with having pulmonary fibrosis, but this was rubbing salt into the wound.

I contacted my MP, Mark Logan, who has been amazing. Since then, I've met regularly with Mark, Louise Wright (APF CEO), Steve Milward (Chair of Bolton Pulmonary Fibrosis Support Group) and my sister, Marie, to talk about raising awareness in Parliament.

Earlier this year, I received an email invitation to Number 10 Downing Street. Well, I immediately dismissed it as a scam and deleted it! It was only when I received a message from someone whose name I recognised asking why I wasn't going to the event that I realised it hadn't been a scam.

Unfortunately, I wasn't well at the time, so I reluctantly missed the event. It transpired that Mark had put my name forward for a Community Champion Award. I was absolutely gutted not to be able to attend and that the opportunity for publicity for pulmonary fibrosis had been missed.

However, a letter arrived in the post from no less than Rishi Sunak himself. It was a lovely letter thanking me for my work to raise awareness of pulmonary fibrosis. I replied and invited him to APF's parliamentary event for MPs later this year. Who knows?

So much has happened since I was diagnosed. Not only can more people living with pulmonary fibrosis now access antifibrotic drugs, we are working towards an improved care pathway so everyone can access the treatment, care and support they need. Much remains to be done, but reflecting on what has already been achieved is satisfying.

If you want to support change, I encourage you to make contact with your MP. If met with apathy, write again and again!"

Welcome Bradley!

APF welcomes Bradley Price as Director of Policy and Public Affairs. He leads APF's influencing work, which aims to put pulmonary fibrosis on the agenda of Parliament and the NHS and to improve the healthcare system at all stages of the pulmonary fibrosis journey. He has a personal connection to the disease, having lost his Nan to idiopathic pulmonary fibrosis in 2014.



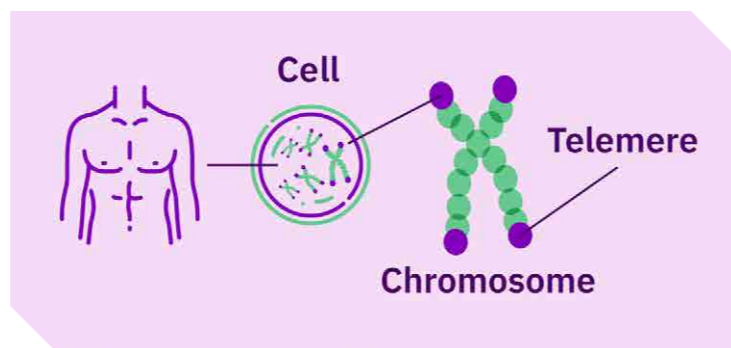
Do you want to be part of improving services for people affected by PF? Get in touch by emailing bradley@actionpf.org.

Research

Pulmonary fibrosis, telomeres and me

Hi, my name is Anna, and I come from a family in which pulmonary fibrosis (PF) appears to be hereditary.

My kind, gentle Grandad died of it in his 70s (I was called home from school to wave to him as they wheeled him out of our house for the last time), and my beautiful, brave Mum died of it at 65 when I was in my 30s. Thankfully, the rest of my family are doing OK, but it's made the scientist in me ask a lot of questions and want to find the answers.



PF is often described as a 'disease of premature ageing', meaning some of the body's cells start to age sooner than they should. Knowing this, imagine my fascination when watching a sci-fi film one Saturday night, and I hear that 'telomeres' are the parts of cells linked with ageing. It set me wondering about my first big question: "What happens if your 'telomeres' are not working properly? Could this cause PF?"

I started reading about telomeres and discovered that they're the end caps of DNA strands. These caps protect the DNA, a bit like how the plastic bits on the ends of shoelaces stop the shoelace from fraying. Millions of the cells in our body divide every day, and to do this, the DNA in those cells has to be copied. Every time the DNA is copied, a little bit of the telomere is lost, and the 'cap' gets smaller.

For most people, the telomeres are long enough to last into old age, but for some, they get too short too soon. When they get too short, it can stop the cell from working properly. If this happens in the lungs, it can result in scarring (fibrosis).

I found this so interesting, and with my background in physics research, I wanted to get involved in PF research. I earned a place to do a PhD in PF genetics research at Exeter University. I work with great people, and together we published my first findings in The Lancet Respiratory Medicine. We found that, in some circumstances, short telomeres can cause idiopathic pulmonary fibrosis.

Our research shows that people who get PF might have lower levels of sex hormones than those of the same age. There also seems to be a link between

the length of people's telomeres and the levels of their sex hormones, so it all fits together.

My next big question is whether sex hormones (like oestrogen and testosterone) might help to stop telomeres from getting too short.

Since early 2022, we've been running a study to find out if people with PF have low levels of sex hormones. We're also investigating if we can safely run a trial to increase the level of sex hormones. It's an enterprise called STARSHIP (Study of Telomeres and Role of Sex Hormones in PF), and we hope it will boldly go far!

After I finish my PhD, I have gained part-time funding from the NHS to continue my research work.

Anna's PhD research is funded by the Medical Research Council.

Every hour of every day, someone around the globe is working towards a better understanding of pulmonary fibrosis, so we can get closer to stopping this disease. At present, it seems pulmonary fibrosis is linked to a wide range of factors, and as such, there is no simple understanding of why anyone gets the disease.



Pulmonary Fibrosis Awareness Month SEPT 2023

September was PF Awareness Month, and we launched a bold campaign, brought PF to parliament, and so much more...



Our national 'Hear My Lungs' campaign was seen on billboards across the UK, **raising public awareness of PF**. This year's campaign had some hard-hitting messages to let people know how devastating PF is. We're determined to create a movement of better awareness for PF, and this bold campaign was just the beginning.



Geoff was the 'breath' behind the campaign and closed PF month with a message of hope.

'Now the month is over, please let's not stop sharing and getting the message out there so that more people can get the help they need. You are braver than you believe and stronger than you seem. Keep going... together we can fight this.'

New support groups were launched in Rhyll, Harlow and the Scottish borders.



We held a briefing session for a group of MPs interested in respiratory health, encouraging them to **support our campaigns for improved healthcare**.

Hundreds of APF supporters contacted their MP about the impact of PF, working to **bring PF to the attention of parliament**.

Supporters up and down the country have been Going the Distance with personal challenges and Creating a Stir by hosting parties. Everyone involved in PF Awareness Month truly has embodied our motto **'Together we are stronger'**.

Our wonderful supporters have so far raised an incredible... £18,400!

Every penny raised from the month will enable APF to carry on our vital work, supporting everyone affected by PF.

Got an idea for PF Awareness Month 2024? Get in touch!



Fiona Prendergast and the Authorisation Team at ACCA did a **sponsored hill climb**.



Alison Milner's **Create a Stir party**.



Jacob Tootell competed a six-hour walk for **Go the Distance**.

The amazing work of Alec, John and Delith: flying the flag for pulmonary fibrosis



Inspiring people across the world

Alec Steele is taking the cricketing world by storm after a video of him playing a match with an oxygen tank on his back went viral worldwide. The video has been seen worldwide; as a result, he's appeared on TV, in newspapers and on the radio.

After his IPF diagnosis at age 80, the first six months were extremely difficult for Alec. With his lung function as low as 30%, moving around and getting upstairs was a struggle, but while attending a hospital appointment, he informed staff that he wanted to be well enough to play one last cricket game. Following months of hard work and with the support of the hospital, last year Alec made his dreams come true and stepped out onto the pitch at St Andrew's. Fast forward to today, and Alec is still out on the pitch playing cricket with his oxygen tank strapped to his back.

As well as becoming an internet sensation, Alec held a charity match and dinner at the end of September. Members of the community came out in full force to support the event, which raised over £4,000. Alec continues to inspire all of us here at APF, and we are so proud to have him as a supporter.



Green fingers funding research

John and Delith Wringe opened their stunning family garden in Hertfordshire this October to over 200 guests. The event not only raised awareness but also an incredible £20,500, which will go directly to helping APF fund groundbreaking research.

John said, 'I helped nurse my lovely, witty father through this condition (IPF) for three years until he died some 30 years ago. We were devastated when I was diagnosed with the same wretched condition in September 2019, exacerbated by learning there still was no cure. As a family, we are determined to contribute to the work being done by APF, which will give hope to families like ours that the next generation will have better treatments, better support and ultimately that a cure will be found.'

Natalie Martin, APF's Community and Digital Manager, said, 'It was evident on the day that the Wringe family had lots of loved ones and friends that wanted to come out in full force to support the event. Guests travelled as far as New York and Yorkshire. It was a spectacular event, and everyone at APF is incredibly grateful to the Wringe family for their support.'

Could you raise awareness and funds in your local community? We'd love to hear from you so please contact our amazing fundraising team and we'll support you every step of the way. Email fundraising@actionpf.org or call **01733 839642**.

Being a carer and yourself

Niki, 51, balances caring for both her brother and dad, alongside her own health challenges. We were blown away by Niki's insights into how she also prioritises her interests and passions alongside her caring role.



Niki

"I speak to Pauline on the support line a lot, particularly when the medical team are saying things I don't understand. Google can be scary, so I'll call Pauline. She breaks it down in a way that makes sense, then I know I don't need to worry about it."



Niki's brother, Michael (name changed for confidentiality), was diagnosed with idiopathic pulmonary fibrosis in early 2023.

'My role has changed from big sis to carer, and it's been an adjustment.'

'It's good for both me and Michael if I have my own sense of self – my own activities and interests. It allows us to maintain our identities outside of the PF world. PF is very much a part of our lives, but there is more to life than just PF. Life still goes on.'

For example, I went to a friend's baby shower the other day, and it's something Michael looks forward to hearing about. He worries that he monopolises all my time, so I think hearing about other things I do helps him to feel less worried about me.

I also care for my dad, who is quite elderly. I speak to doctors, manage transport, and things like that. It has been a challenge trying to support

them both. Sometimes, I have to prioritise my brother as my dad has other people to help him, even though he prefers me to.

Michael has carers now, who have lessened my load considerably. Before he had them, it was overwhelming. I was constantly on the go and really tired. I have fibromyalgia and chronic fatigue syndrome, so I have to check in with myself and make sure that I'm okay. I've found that if I use all my energy in my caring role, it leads to burnout. And then I can't do much at all.

If I'm not doing okay, I will reach out to family and friends, church group and the APF support line. I can also speak to my advocate when things get difficult. She has been a real lifeline, helping my brother and me better understand life with PF. Having that support makes all the difference.'

'If I use all my energy in my caring role, it leads to burnout.'

The APF support line offers information, signposting, or a friendly ear when you need one. Call the support line team on **01223 785725** or email supportline@actionpf.org.

Changing pulmonary fibrosis healthcare

A huge thank you to the 1,000+ people who completed our survey in June. Your insights are essential to improving pulmonary fibrosis treatment, care and support.

Survey summary

What we did:

We asked people affected by pulmonary fibrosis (PF) about their experiences, what's important to them, their challenges, and how we can help. You rose to the opportunity, and we had a fantastic number of responses.

1,025

people responded to the anonymous survey.

248

people participated in workshops and interviews.

Using your words, we've been building a picture of what life with PF can look like for different people.

A snapshot of what you told us:

"Everything takes a lot longer."
Doing the simplest things, like walking around the house, are often overwhelmingly difficult for people with PF.

65%

have not been spoken to by their healthcare team about taking part in research.

"I put a brave face on all the time but inside I am falling apart."

People expressed frustration that PF tends to be grouped with conditions like COPD and asthma when, in fact, they need very different healthcare support.

33%

of patients said an information leaflet at diagnosis would have made a difference to them.

What we're going to do next:

In your responses, you've told us what works and what doesn't in PF treatment, care and support. Knowing this, we will work to change it for the better, to improve the lives of people affected by PF.

#OneVoiceILD is the network of people affected by PF, healthcare professionals, MPs and industry professionals working together to bring about this change.

The survey is just the beginning. Over the coming months, there'll be further opportunities to get involved with #OneVoiceILD to help us bring the changes we all want to see.

To be continued...

Don't miss out on #OneVoiceILD updates.

- Email ovild@actionpf.org
- Follow us on social media. Find us on twitter at #OneVoiceILD
- Sign up for our e-newsletter by scanning the following QR code:



General enquiries:

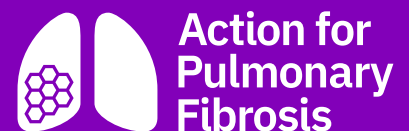
01733 839642
info@actionpf.org

Action for Pulmonary Fibrosis, Stuart House,
St John's Street, Peterborough PE1 5DD

Follow us on socials:



Registered Charity SC050992 in Scotland.
Registered Charity 1152399 in England and Wales.



www.actionpf.org

What do you think about Insider?

We want to make sure we're using our resources in a way that gives you the best information and support. To do this, we'd love to hear your opinion on Insider to know if we're getting it right.

We'd really appreciate you taking a few minutes to answer some quick questions. We welcome opinions from anyone who reads Insider, no matter what your personal connection is to pulmonary fibrosis.



(All answers are anonymous)

To complete the survey, either:



Return your questionnaire stamp-free and without charge to: **'Freepost ACTION FOR PULMONARY FIBROSIS'**

(Please ensure you use capital letters and there is no need to include our full postal address).



Answer the questions online by scanning the QR code or by visiting:

forms.office.com/e/sQS9TwDMV5



1. What is your personal connection to pulmonary fibrosis?

(please tick as appropriate)

- I have pulmonary fibrosis
- I am a healthcare professional
- I care for someone with pulmonary fibrosis
- I am a friend/family member of someone with pulmonary fibrosis
- I cared for, or am the friend/family member of, someone who died of pulmonary fibrosis
- Prefer not to say
- Other (please specify in box below)

2. Insider helps me and my family/friends to:

(select up to three options)

- Learn more about pulmonary fibrosis
- Live well with pulmonary fibrosis
- Find support Feel hopeful
- Feel like part of a community
- Get involved in the pulmonary fibrosis community
- Stay up-to-date with pulmonary fibrosis activities and events
- Find out about the latest research
- Other (please specify in box below)

3. What Insider content do you prefer to read?

(rank each feature from 1 to 9, with 1 being the most preferred, 9 being the least preferred)

- Steve's column
- In-depth stories from people affected by pulmonary fibrosis
- Short stories/quotes from people affected by pulmonary fibrosis
- Features by experts
- Informative articles with practical advice
- Fundraising
- Research
- Campaigning
- Where to find support/support offered by APF
- Updates on APF's work and activities e.g. Pulmonary Fibrosis Awareness Month

4. How likely are you to recommend Insider to other people with pulmonary fibrosis, their families and friends?

(select one option)

- Very likely
- Somewhat likely
- Unsure
- Somewhat unlikely
- Very unlikely

5. How could we improve Insider?

(select up to three options)

- More short articles (less than two-minute read)
- More long articles (more than two-minute read)
- More real-life stories from people affected by pulmonary fibrosis
- More factual/informative/expert articles on living well with pulmonary fibrosis
- More information and news about pulmonary fibrosis research
- More information about APF's work
- More about NHS care for pulmonary fibrosis
- More about support groups
- Other (please specify in box below)

6. Do you have any other comments or suggestions about Insider?

Thank you for completing the survey!



Action for Pulmonary Fibrosis

