

Insider

Living well with pulmonary fibrosis



Action for
Pulmonary
Fibrosis

Spring/Summer 2025



We are more than
our challenges:
Dave's story

Have your say in our
2025 survey

How does research
benefit me?

Summer holiday ready

Support for carers

PF month 2025

actionpf.org

A message from our CEO

I can't quite believe we're already approaching the summer months; it feels like just yesterday that I joined Action for Pulmonary Fibrosis (APF) back in September 2024. Time has flown by, and over these past eight months, I've been both inspired and humbled by the strength and generosity of our community.

Getting to know our community

Getting to know so many individuals who make APF what it is – our passionate volunteers, tireless fundraisers, and committed supporters – has been one of the most rewarding parts of my role so far. I've also had the privilege of learning more about the direct and lasting impact our work has on those living with pulmonary fibrosis (PF). Every story I've heard and every person I've met has reaffirmed why we do what we do.

Moving forward

As we look ahead, I'm excited to share that we're working on a bold new five-year strategy. One that will shape how APF grows our impact, deepens our support, and works toward a world where no one faces PF alone. This strategy builds on the strong foundations laid by our 2024 plan, which provided a valuable period of transition and reflection. Since then, the needs of our community have evolved, our ambition has grown, and our organisation has developed in new and exciting ways.

What's emerging is a forward-looking roadmap that marks a real step change for APF: a clearer focus, a stronger delivery model, and a greater ambition to transform the lives of people affected by PF. This new strategy responds directly to urgent needs and reflects our deep commitment to leading change across support, care, and research.

Over to you

Of course, at the heart of everything we do is you – the PF community. Back in 2023, your voices in our national survey helped us influence policymakers and shape better care.



Every story I've heard and every person I've met has reaffirmed why we do what we do.



Daniel Saxton

But we know there is still much more to do. That's why we're asking again for your time and insight. If you've received this magazine by post, you'll find this year's survey enclosed. If you're reading digitally, just follow the link on page 12. Your contribution truly helps us make change happen.

This edition of Insider is packed with updates from across APF and inspiring contributions from people in the PF community. With sunnier days ahead, many of you might be planning a break, so don't miss our article on travelling with PF for tips and advice.

However you're spending the summer months, I hope you find moments of joy and sunshine.

Thank you for your continued support.



Best wishes,

Daniel Saxton
Chief Executive Officer
Action for Pulmonary Fibrosis

Scan QR codes to visit web pages

Open the camera on your smart phone or tablet. Point the camera at the QR code. Make sure you can see the whole QR code on your screen. When a link appears on your screen, tap to visit the web page.

You can also call us on 01733 839642 about anything in this magazine.



Save the date: September is Pulmonary Fibrosis Awareness Month

The month of September marks Pulmonary Fibrosis Awareness Month (PF Month). This globally recognised campaign aims to shine a spotlight on the pulmonary fibrosis (PF) community and raise awareness of this devastating disease.

We want to bring communities together, inspire action and encourage positive change.



What we're doing in 2025

You may be familiar with our campaigns from previous years, where our focus has been on the signs and symptoms of PF. This year, we're doing things a little differently.

We want to give a voice to the PF community and create a space for anyone affected by PF to share their story.

People affected by PF will be at the heart of our campaign this year, and we want YOU to get involved by sharing your PF story.

Through the power of storytelling, we want to:

Highlight how diverse the PF community is.

Emphasise that people with PF are not just a number; there are individual stories to be told.

Show that every breath counts.

Get involved

Share your story

Raise awareness using your voice. Be one of the first to hear about how you can share your story.

✉ communications@actionpf.org ☎ 01733 839642

Go the Distance

Walk, run or move however you like, in our popular challenge. Every step taken and every pound raised truly makes a difference. Register now.

✉ fundraising@actionpf.org

☎ 01733 839642

PF-friendly sponsors

We're looking for a business that has benefited the PF community to sponsor our PF Month activities. Has a product or service made your life with PF a bit easier? We'd love to hear about it.

✉ fundraising@actionpf.org

☎ 01733 839642

We're always blown away by the support we receive each September during awareness month from the incredible PF community, and we're excited to share a round-up of all this year's activities in the next issue of Insider magazine.

Finding your way Dave's story



Dave and his wife, Cara

Former personal trainer, Dave was diagnosed with idiopathic pulmonary fibrosis (IPF) this year, at the age of 50. Dave lives in Gloucestershire, and his countryside adventures with oxygen in tow give him purpose. His story is a reminder that each journey with pulmonary fibrosis (PF) is unique, and finding what works for you is important.

'My wife, Cara, and I recently set off on another countryside adventure. Now, to some, that might sound like just a simple getaway—a break from routine, a chance to breathe fresh air. But for me, it was so much more. It was a declaration of freedom, a refusal to be defined by limitations, and a reminder that life, no matter how challenging, is still filled with beauty waiting to be embraced.'

PF may have taken away the ease of movement I once had, but it has not taken away my spirit. I carried two oxygen cylinders and an electric two-wheel scooter, not as symbols of what I've lost, but as tools that allow me to continue experiencing what I love.

The truth is, life is not about what we can no longer do; it's about finding ways to still do what makes our souls come alive.

I won't sugarcoat it, this journey is hard. It's frustrating. It's filled with moments of exhaustion, of doubt, of the overwhelming weight of medical appointments and treatments that sometimes feel like they're pulling me away from actually living.

It's the strain on a marriage: the unspoken worries, the adjustments to a new reality neither of us signed up for.

However, in the heart of the countryside, away from hospital walls and sterile hallways, I found something that no illness can take away, peace. The rolling hills, open sky and the whisper of the wind in the trees remind me that I am still here. I am still me.

I still have a purpose. We all do.

Life is worth fighting for. There will be moments of frustration, moments where we grieve what once was, moments where the weight of it all feels unbearable.

But we must push forward. We are more than our challenges. We are more than our setbacks. As long as there is breath in our lungs, assisted or not, we have a reason to keep going. Whatever that looks like for each of us.'

“
It's the battle of the mind as much as the battle of the body.
”

Thank you Dave for sharing such a powerful and inspirational story with us. We are truly grateful. If you're interested in sharing your story, please get in touch.

✉ communications@actionpf.org
☎ 01733 839642

Are you recently diagnosed?

Book your place on our new webinar 'An introduction to navigating the PF journey.'

Hear from healthcare professionals and people living with PF about:

- Coming to terms with your diagnosis
- How to tell friends and family
- Where to get support and information

And have your questions answered live.

📅 Book now:
bit.ly/navigatingpf



We'll run the same webinar every month, so you can choose which month you join.



“

I am still here.
I am still me.
I still have a purpose.
We all do.

”

Research gives us all hope: how every study brings us closer to creating a brighter future for everyone with pulmonary fibrosis

How does pulmonary fibrosis research help me?

If you or someone you love has pulmonary fibrosis (PF), you might wonder, 'How does this research actually benefit me?', or, 'Is it even relevant for my type of PF?'.

Every study helps move us towards better treatments and care for all types of PF. Whether it focuses on a specific type of PF, symptom management, or support for caregivers.

Research is not just about science; it's about hope, progress, and the promise of a better tomorrow. Every research project adds a new piece of the jigsaw, building our understanding to find kinder, more effective treatments.



£30 could support one hour of PF research by an APF-funded scientist.

DONATE NOW TO MAKE A DIFFERENCE
bit.ly/apf-donate

Every discovery opens new doors

A lot of research into new drugs or treatments starts by focusing on just one type of PF. This is often idiopathic pulmonary fibrosis (IPF), but over time, researchers may find that these drugs can help people with other types of PF too. This has already happened with medications like nintedanib and pirfenidone. They were first approved for IPF but are now being used for the treatment of other types of PF too.

This is why every bit of research matters, because what works for one type of PF might help others too.

If you see a study and think, 'Why is it always focused on IPF?', researchers have to start somewhere, and IPF is often the largest pool of people that they can reach first. However, all research has the potential to benefit other forms of diagnosis too, and all research helps us to learn more about the disease. Even if research fails, every bit of new information builds on what came before. Ultimately, everything helps us find new and better treatment options.



Finding out what doesn't work is just as important as finding out what does.



Research isn't just about new treatments, it's about living better now

Not all research is about finding new drugs. Some studies focus on making life easier for people living with PF. These studies might look at things like:

- Managing breathlessness
- Reducing a cough
- Dealing with tiredness
- Mental health and wellbeing
- How caregivers can get better support

These studies apply to anyone with PF, no matter what diagnosis someone has.

By taking part in research, or by donating to our research, people with PF and caregivers help us to understand the best ways to live with PF. The more we learn, the better we can support everyone to live as well as possible with the disease.



All research help moves us forward

Research isn't just about finding a cure, it's about making life better for people living with PF today and in the future. Whether it's a drug trial, a study on oxygen therapy, or research into symptom management, every bit of progress benefits the PF community.

The fight against PF is far from over, but every study brings us closer to improved care, better treatments and one day stopping PF in its tracks.

Progress is happening now, and you can be part of it.

Help us to shape a future where PF is no longer a life-limiting disease but a challenge that can be overcome.

So, if you have PF, no matter what type, or if you're a caregiver, know that research is working to help make things better for you.

You can be part of the progress

You have told us that it can be hard to know which research studies might be available to you. That's why we developed our **Study Finder**, an easy to use tool to help you find opportunities in the UK. You can look at the research currently happening, stay up-to-date with results, and consider getting involved, because together research is moving us forwards.

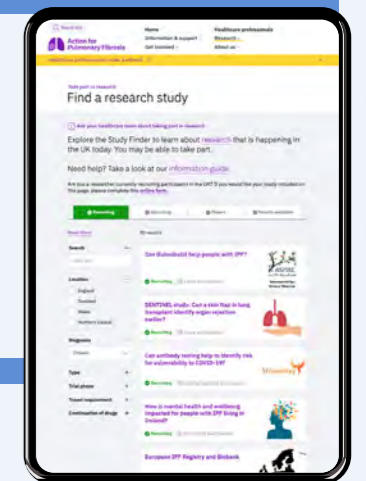


SCAN ME

Take a look at our Study Finder

bit.ly/apfstudyfinder

If you don't have access to the internet and a family member or friend can't help, you can ask your healthcare team to use the Study Finder with you. You can also talk to your healthcare team to see which studies might be suitable for you.

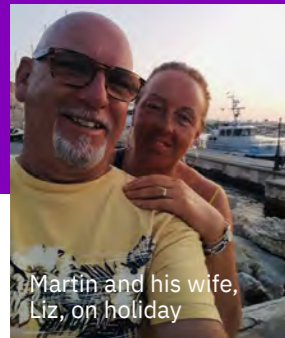


“Every breakthrough starts with someone willing to take part.”

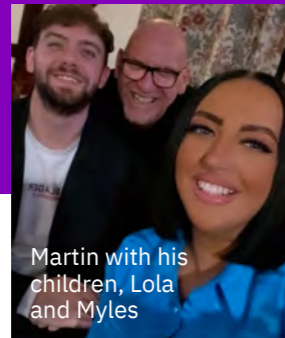
‘Just one phone call to APF meant the world’

Lola’s tribute to her dad, Martin

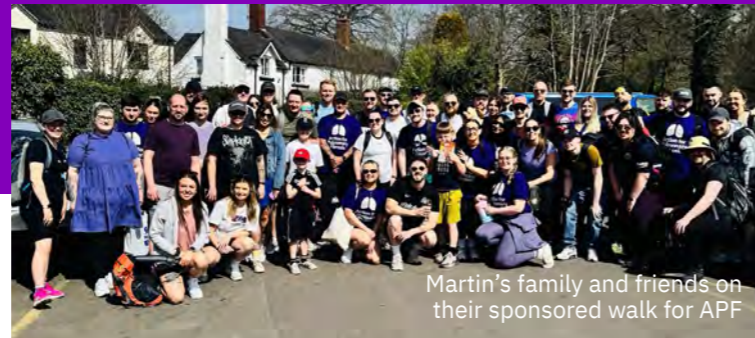
‘My wonderful Dad, Martin, was an incredible human being. Kind, caring, and he had an amazing energy to be around.’ Lola, 33, shares memories of her dad, who sadly died from pulmonary fibrosis (PF) in January 2025.



Martin and his wife, Liz, on holiday



Martin with his children, Lola and Myles



Martin’s family and friends on their sponsored walk for APF

Martin was a beloved husband to Liz, and dad of two, Lola and Myles. He worked supporting others in NHS mental health services before retiring at 60. After retiring, he continued helping others with gardening and odd jobs.

‘He would walk into a room and if it was boring, he’d light it up and make everybody laugh.’

In 2022, Martin was diagnosed with PF. His first symptom was a dry cough. From the point of diagnosis, Martin was determined to live life to the full. Even when he needed oxygen, he didn’t let it stop him from enjoying holidays and time with his family.

Liz, Martin’s wife and best friend of 42 years, was his constant support, always ensuring he was loved and cared for.

As his health declined, Martin was able to celebrate his 63rd birthday on 29 January this year, just two days before he died.

During the hardest times, Lola reached out to APF for support. She credits Jo, our Senior ILD Nurse, for making a real difference.

‘I’ll always be grateful to Jo. Just one phone call meant the world to me because she actually cared. She gave me the knowledge to make sure Dad was getting the care he needed.’

Lola wanted to give back to APF and set her mind to raising awareness and vital funds. Lola organised a sponsored walk for APF, supported by her colleagues at Bally’s Interactive. Carrying the weight of a mobility oxygen tank to symbolise the daily struggles Martin faced, they took on a 10-mile route and raised over £5,500.

“Research is the only way we’ll find a cure. Charities like APF give people hope and help people through these difficult times.”

“It was an honour to care for my dad, to give something back to him after everything he gave to us.”

‘Dad didn’t like any fuss, but when I told him 40 people had signed up, he burst into tears. He was so proud, and I know he’d be proud of everything we’re doing now, too.’

Lola and her family are determined to continue raising awareness.

If you’d like to help APF continue supporting families now and into the future – whether through a donation or in memory of a loved one – please contact our fundraising team.

✉ fundraising@actionpf.org ☎ 01733 839642

Together, we can make sure no one faces pulmonary fibrosis alone.

Challenge your company to join APF this summer



Do you know a company looking for a team-building challenge with a difference this year?

We’re searching for companies to take on a team challenge to raise vital funds for our work and we’d love your help. Whether it’s scaling the UK’s highest peaks, conquering an obstacle course, or embarking on an overseas trek, there’s something for everyone! These challenges offer an incredible opportunity for teams to bond and boost the public image of the company, all while making a real difference for people living with pulmonary fibrosis.

Tell us about companies you know that might be ready to take on a challenge and support our cause. Maybe you or a family member works for a company that might be interested? Or do you know a business that is looking for a charity partner?

From physical feats to unforgettable memories, these fundraising events are a fun and meaningful way for companies to make a difference.



If you have any connections to companies you think may be interested, ask them to contact us.

☎ 01733 839642

✉ fundraising@actionpf.org

🔗 bit.ly/apfcorporate



SCAN ME

Play our weekly lottery

Take your chance to win up to £25,000



Make a difference today by playing our weekly lottery and securing your chance to win the jackpot of an incredible £25,000! Tickets are just £1 each and every purchase directly helps fund vital research and provide expert support to individuals and families living with pulmonary fibrosis.

It only takes **five minutes to sign up**, but your impact could last a lifetime, and secure you the jackpot of £25,000.

Play today. Change lives.



SCAN ME

Get your ticket now

🔗 onelottery.co.uk and search ‘Action for Pulmonary Fibrosis’ in the listed causes



The unseen journey: emotional wellbeing and pulmonary fibrosis

Living with pulmonary fibrosis (PF) brings challenges that go beyond physical symptoms. As a clinical psychologist, I often remind people that managing lung conditions can be stressful, and it's important that you get the support you need.

This page is an introduction to managing your emotional wellbeing if you're affected by PF. While we can't cover everything about mental health and your unique personal circumstances in these few pages, we hope to open the door to this important conversation.

How can PF affect mental health?

Whether you have PF yourself, or your loved one does, the disease arrives without invitation, disrupting your normal life. It can take away activities you enjoy, give you tasks you don't want and bring symptoms that can be difficult to live with.

PF needs your time, energy and strength, on top of what normal life already demands. This extra demand can affect your mental health.

Feelings as messages

These emotions are normal human responses to illness. They are understandable, given what you are dealing with.

Whilst they can be uncomfortable, they are also important messages that your emotional wellbeing needs care and support, just as your physical symptoms do.

What can I do?

You've already shown incredible strength. Recognise the courage it takes to live with PF. There is support available, as well as things you can do yourself to help manage difficult emotions in the moment.

Read about ways to care for your wellbeing when things get tough.


NHS Every Mind Matters

[nhs.uk/every-mind-matters](https://www.nhs.uk/every-mind-matters)

Reach out to loved ones to talk about how you're feeling. Many people find that sharing their worries can be a great source of comfort and a reminder that they are not alone with their struggles.

When to seek additional help

Consider speaking to a healthcare professional if you are struggling to manage your mental health by yourself.

 Your GP or keyworker may be the best place to start.



Dr Elaine Smallman is a clinical psychologist who has been working with people with lung disease for 12 years. Elaine works in the Northern Health and Social Care Trust in Northern Ireland.

Resources for additional support


Speak to someone

APF Support Line

See next page for details.

Samaritans (24/7)

 116 123

 jo@samaritans.org

Online resources

NHS mental health information

 [nhs.uk/mental-health](https://www.nhs.uk/mental-health)

Mind

 [mind.org](https://www.mind.org)

Remember, you're not alone on this journey

Living with PF is challenging, but taking small steps to care for your mental health can make a real difference. Whether it's a brief mindfulness exercise, talking with a friend, or contacting a support service, each action matters.

Your feelings are valid, and seeking help isn't weakness—it's a strength. You aren't alone on this journey, and a community of professionals and loved ones are here when things feel overwhelming.

APF Support Line: for all PF journeys



Pauline, APF Support Line Manager

“

Talking to you today has given me hope. I know we can actually lead some sort of life with this.

”

Robert*

Message from Pauline, APF Support Line Manager:

Our support line is here for you, whether you're living with the disease, caring for a loved one, or working as a health professional.

No question is too small, no concern unimportant. You deserve someone who will truly listen. Someone who will respond with care and expertise. We're not for emergencies; we're here for all those important moments in between, helping you find your way forward.

You don't need a specific reason to call – if PF affects you, that's reason enough.

People reach out to us for many reasons:

'I've just been diagnosed and don't know what this means for me.'

Our support line team listened to Seren's* experiences, giving her time to process her diagnosis. We sent an APF recently diagnosed information pack, and introduced Seren* to her local support group.

'My father is struggling with breathlessness and I feel helpless.'

We supported Rohan* to talk to his father about getting help with his breathlessness. We also worked through practical strategies to manage breathlessness there and then.

'I struggle to get what I need from my GP.'

The team supported Alison* to advocate for herself in her GP appointment. We helped her plan an explanation of her concerns, and questions about what happens next.

Our team includes a specialist nurse with expertise in pulmonary fibrosis. We can provide:



Accurate information about PF and living well



Guidance on finding local services, social support and financial assistance



Emotional support



Information about APF's other services, including telephone befriending and campaigning to improve PF care

“ When you're ready to talk, we're ready to listen. ”

We're here 9am-5pm, Monday to Friday.

 01223 785725  support@actionpf.org

*names have been changed in this article for confidentiality

Help shape the future of care for people with pulmonary fibrosis

Now is your chance to share your experience to help make positive, lasting change in pulmonary fibrosis (PF) care across the UK. Please complete our 2025 Pulmonary Fibrosis (PF) State of the Nation Survey today to help influence change and ensure PF is recognised and prioritised.

In 2023, over 1,000 people affected by PF shared their experiences through the APF Lived Experience Survey. Thanks to your input, we worked alongside people affected by PF, healthcare professionals and service planners to create a new optimum care pathway for PF. The pathway was launched in England, and now similar pathways are being developed for Northern Ireland, Wales, and Scotland.



Now it's time to take the next step

We hear all too often that:

- Diagnosis takes too long
- It's difficult to get appointments
- Waiting times are unacceptable
- Not enough people know about PF

This needs to change, but we need your input to make sure people who plan these services listen to us and take action.

The 2025 PF State of the Nation Survey is your chance to show why urgent change is needed and to make the optimum care pathway the standard across the whole of the UK. By sharing your feedback, you'll help to persuade those who plan these services to improve the future of care for people with PF.

The survey aims to capture the voices of everyone touched by PF. **Whether you're living with the disease, caring for someone who is, or grieving the loss of a loved one, your insights are crucial for driving urgent improvements in care, diagnosis and support.**

Please also remember that we want you to share your individual stories for our **PF Month campaign**. See page 3 for more details.

Sharing your stories and completing the 2025 PF State of the Nation survey will strengthen our voice. Together, we can make a difference in PF care across the UK.

Complete the survey today

bit.ly/apfsurvey

Or, complete the enclosed paper survey and return using the freepost address on the back.

The survey closes on **30 June 2025**.

Please complete as soon as possible to ensure your feedback is registered.



For more information, please contact us.

01733 839642

policy@actionpf.org

Thank you to the incredible pulmonary fibrosis support groups

We are proud to shine a light on the generosity and dedication of three incredible pulmonary fibrosis (PF) support groups who have gone above and beyond to raise funds and awareness for PF.

Nottingham Pulmonary Fibrosis Support Group presented our CEO, Dan Saxton, with a donation of **£1,000**, raised through heartfelt fundraising and memorial donations.



Special thanks to **Betty Mollet and her son, Garry**, who raised funds in memory of Grenville Mollet, kindly donating **£450** to APF.

We also extend our thanks to **Alan Archer**, who completed a sponsored swim and raised **£400**, split equally between APF and the Nottingham group. In addition, the group donated **£350** to APF's research fund.

'We are truly humbled by the generosity of the Nottingham group,' said CEO Daniel Saxton. 'It's inspiring to see communities come together to support each other and fund better treatments.'

In **North Wales, Sue Hill** and the talented **Knit and Natter Group** raised an incredible **£3,000** for APF by selling handmade items at Rhuddlan Library, Glan Clwyd Hospital, and St. Mary's Church.



The group of 15 meets weekly, and their dedication is inspired by Sue's son-in-law, **Andy Davies**. He was diagnosed with PF at just 42 and now leads the North Wales Pulmonary Fibrosis Support Group.

'I'm blown away by their commitment,' said Andy. 'Their passion not only raises funds but also brings people together and spreads awareness. It's my dream that one day we'll put a stop to PF—and supporting research brings us closer.'

We also wish to thank **Alan Tratt** and the **Leicestershire Pulmonary Fibrosis Support Group**, who donated a fantastic **£1,500** to APF. Alan, diagnosed with IPF in 2016, joined the group in 2017 and took over as leader after the passing of Mick Coe. Since then, the group has grown significantly, regularly welcoming over 30 members. 'In 2017, APF was still in its early days, but even then, it provided crucial information and support,' Alan shared. 'Now, we continue to raise funds through coffee mornings, funerals, and generous donations. Every contribution helps support research and those living with PF.'



These support groups and their members are a testament to the strength, compassion, and determination found in PF support groups across the UK. From knitting and swimming to coffee mornings and community events, your efforts help fund research, raise awareness, and bring people together.

Want to fundraise in your community?

If you'd like to raise funds and awareness for pulmonary fibrosis in your local area, we'd love to support you!

bit.ly/apfcommunity

01733 839642

fundraising@actionpf.org

Together, we can make a real difference.



Summer holiday ready: an introduction to travelling with PF

Many people living with pulmonary fibrosis (PF) enjoy travel, whether it's a short drive to visit family or an international adventure. Start planning your next trip with this introduction to PF travel, featuring insights from experienced travellers.

Before booking

- Speak to your interstitial lung disease (ILD) team about your travel plans. If you don't have an appointment booked, call the hospital and ask to speak to the team.
- Check that travel companies can accommodate your needs.
- The environment can affect your PF symptoms. For example, very hot, cold or humid weather, or places at high altitude can make it more difficult to breathe.

Insurance and documents

- Get suitable travel insurance. Many people shop around to find the policy that works for them.
- Get any documentation required by travel companies or the place you are visiting.

Holidaying with oxygen in the UK

- If you need oxygen to be installed at your accommodation, arrange this with your usual oxygen supplier.

Holidaying with oxygen abroad

- Oxygen equipment provided under the NHS Home Oxygen Service can't be taken outside the UK. However, there are other UK oxygen companies that allow their equipment to go abroad. Ask your supplier for details.
- If you need oxygen equipment to be installed at your destination, you will need to do this through a local supplier. Your UK oxygen supplier may be able to advise you how to do this, as it will vary depending on your destination.

Comfortable travel

- Consider booking special assistance for public transport.
- Plan rest breaks between activities and throughout your journey.
- Check accessibility of service stations, terminals, ports or stations, including the distance to the toilets from waiting areas.
- Know the location of local healthcare providers.
- Consider if you might need any mobility aids to get around, like a wheelchair or electric scooter. You may be able to hire them in some places.



'If I'm in a queue, I get quite stressed. I now do my yoga breathing exercises to keep my brain from thinking about my breathing.'

Alicia



Packing essentials

- Pack any medications in the original packaging. Consider taking extra in case your journey is delayed.
- Take a copy of essential contact details, including your ILD team and oxygen supplier.
- Get copies of your prescriptions and any other medical documents you may need.

Travel top tip

Start planning your trip well before you plan to travel to give yourself enough time.

Planning to fly?

There is less oxygen in the aircraft cabin, which can make breathing more difficult for some people with PF. If you plan to fly:

- Check with your ILD team that flying is safe for you. You may need some additional tests to make sure.
- Check with the airline what documentation you might need to travel.
- Some people might need oxygen during a flight, even if they don't usually need oxygen at home. If your ILD team says you need oxygen during the flight, check what equipment the airline allows. Then speak to your oxygen supplier to help you arrange this.



If you take certain medications, you might need to use the bathroom more frequently. I choose an aisle seat close to the bathrooms just in case.

Philip

Travel with oxygen top tip


If you have a portable oxygen concentrator, make sure you have enough charge for the journey, and any spare parts, like additional tubing, that may be needed.



SCAN ME

Be kind to yourself if you can't do everything you used to do. You might need to find new ways to enjoy your trip at a different pace. If you're travelling with someone, you might want to talk to them about any support you might need. Enjoy your trip!

Remember, this is just an introduction — find more information in our travel guide.

bit.ly/apftravel  01733 839642 for a printed copy

Support for family, friends and unpaid carers

Supporting someone with pulmonary fibrosis (PF) can be a rewarding but challenging experience. Action for Pulmonary Fibrosis is here for you too.

Am I a carer?

A carer is anyone who looks after a family member, partner or friend without pay. If your loved one wouldn't be able to cope, physically or mentally, without your support, you are a carer.

Some people may not like to use the term carer as they are, first and foremost, family members or friends. However, it can be helpful to identify as a carer. This can allow you to access support and information for both you and the person you support.



What support can I get?

Free annual carer's assessment: You are legally entitled to this assessment that looks at your wellbeing and needs as a carer. It's not a test of your caring skills. The help available ranges from home adaptations and practical assistance to advice about financial support. Many people find it helpful to get an assessment early on to prepare for changes in circumstances.

Find out more at bit.ly/pfcarersassess

APF Carers Community: Join our community to receive useful information, updates, and an invitation to our monthly online support group. This is a safe and confidential space to share your experiences and meet others in a similar situation.

Join now bit.ly/apfcarers

Financial help: You may be able to claim certain benefits if you are a carer, depending on your individual circumstances.

Register as a carer with your GP: This entitles you to free flu vaccinations and other health benefits.

Helpful contacts:

Carers UK carersuk.org
(0808 808 7777)

Carers Trust carers.org
(0300 772 9600)

NHS information for carers bit.ly/nhs-carers
(0300 123 1053)

Here to help

Remember, if you're supporting someone with PF, Action for Pulmonary Fibrosis is here for you too.

 support@actionpf.org
 **01223 785725**