Help us be there for people like Mike and Lara this Christmas.

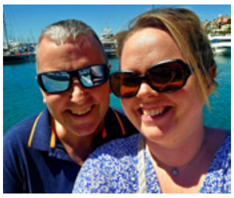
Christmas Appeal

Lara first noticed symptoms in her partner of eight years in January 2024, when Mike came home from work and looked ill, unable to catch his breath.

As we hear from many living with pulmonary fibrosis (PF), Mike and Lara had to push for a diagnosis and care, with one doctor saying it may be anxiety and suggesting to 'take up yoga'. Mike received his diagnosis of idiopathic pulmonary fibrosis in May 2024.

'I had never even heard of pulmonary fibrosis,' Lara said. 'We received nothing from the hospital, I had to seek out support myself, and I found APF.'

Action for Pulmonary Fibrosis (APF)'s support team was able to provide vital information about Mike's condition and we were also at the end of the phone when Lara needed support.



'APF's holiday advice meant we could go travelling. We drove all through France, Belgium, the Netherlands and Germany. We loved travelling together.'

In August Mike caught an infection meaning he had to go into hospital, and he then caught Covid. Mike asked Lara if she would marry him while he was ill in hospital. When the chaplain said they could be married the next day, Mike was adamant that it was going to happen. *'I think he knew he was going to die soon,'* says Lara.

Lara managed to arrange the wedding in only 24 hours, and they got married in hospital on Friday 27 September. *'It was heartbreakingly beautiful,'* says Lara. On Sunday 29 September, Mike sadly passed away aged 51.

'I always loved him and always will do. We thought we had plenty of time. We heard of people living with PF for 10 years, we hoped he would make it to 61.'

APF support services help over 15,000 people each year. From our Support line and telephone befriending, to information resources and working with community-based support groups, our dedicated team provide a lifeline to people living with PF and their families.

We will continue to work tirelessly to be there for the estimated 210,000 people in the UK affected by PF, through our vital support services and groundbreaking research.

'APF is needed because sufferers and family members don't have anything else. There is no one else with the experience or knowledge, so without them we'd be in the dark,' says Lara.

Help us be there for people like Lara and Mike so nobody has to face this devastating disease alone. Donate today to help us change lives.

Thank you,

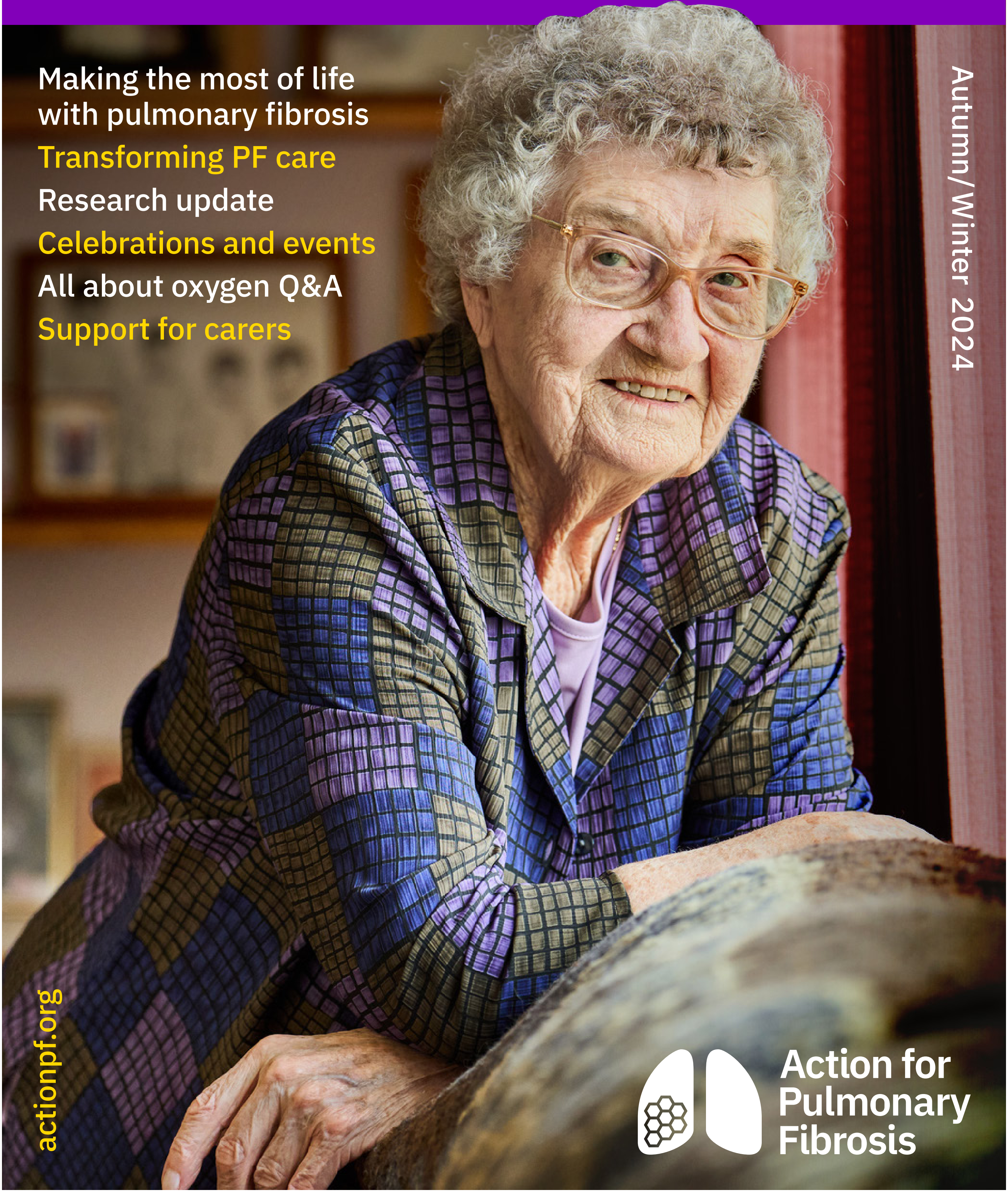
Katherine Wright
Individual Giving Manager

CLICK HERE TO DONTATE

If you would like to donate by cheque please make your cheque payable to Action for Pulmonary Fibrosis and post to: Action for Pulmonary Fibrosis, Stuart House, St John's Street, Peterborough, PE1 5DD

Insider

Living well with pulmonary fibrosis



Making the most of life with pulmonary fibrosis

Transforming PF care

Research update

Celebrations and events

All about oxygen Q&A

Support for carers

Autumn/Winter 2024

actionpf.org

Action for Pulmonary Fibrosis

Welcome to Daniel Saxton, our new CEO!

Daniel Saxton, our new CEO

This September, during Pulmonary Fibrosis (PF) Awareness Month, we were excited to welcome Daniel Saxton as our new Chief Executive Officer.

Dan joins us from the prestigious heart and lung hospital, Royal Papworth, where he spent the last 12 years. Dan has always ensured that the voice of the patient is at the forefront of his work. His leadership extended beyond charity management to directing communications and business development – all while keeping the patient experience at the heart of every decision.

Dan has already hit the ground running, meeting with our dedicated team across the UK and attending significant events such as the European Respiratory Society Congress and the ILD-IN conference where he has been championing improved care for patients with PF. His expertise, combined with his passion for improving lives, makes him the perfect person to lead Action for Pulmonary Fibrosis (APF) through an exciting phase of growth.

Dan expressed his excitement about his new role:

'I am thrilled to be joining such a dedicated team at APF. My focus will be on increasing our support for people living with PF right here right now, working with partners to improve care and drive forward essential research to tackle this disease. I look forward to visiting our support groups across the country and hearing directly from the community about how we can best support you.'

Dr Mike Stubbins, our Chair of Trustees, shared his enthusiasm about the appointment:

'Dan has the ideal mix of skills, experience and commitment to lead APF at this critical time. His deep understanding of both the challenges faced by patients and the complexities of charitable leadership and the NHS will be invaluable as we continue to grow and support the PF community. Dan is already focused on strengthening APF's mission and ensuring that everyone affected by PF receives the support, care and attention they deserve.'

Leading on our new strategy

Dan's arrival also coincides with the launch of APF's **new six-year strategy**. Our goal is that everyone living with PF in the UK will have a timely diagnosis, access to effective treatment and care, and ongoing support. To achieve this, we're focusing on three main aims between 2024 and 2030:

Provide information and support for all

Grow and unite our communities to drive change

Ensure more people at risk of PF know the signs and symptoms

Together, we will stop lives being lost to PF. Find out more about our strategy by visiting **bit.ly/APFstrategy** or click the button.

CLICK HERE

PF Month 2024

In September people across the UK joined us to spread the word about the reality of pulmonary fibrosis (PF). PF devastates lives, and we can't change this without our incredible community. Here's just a snapshot of what happened.

76 support groups across the UK were busy putting up over **800 awareness posters** and banners in clinics, GP surgeries and pharmacies.

Over 14,000 people visited our PF Month web page to read about real PF experiences and learn about disease symptoms.

A whopping 35,000 new people visited our website.

We want to thank every single person who flew the PF flag in September, raising both funds and awareness. Every penny will go towards funding life-changing research, which will help more people with PF to live well for longer.

We're already looking ahead to PF Awareness Month 2025, and we'd love you to join us again. What we've achieved together is incredible, but we can't stop now. More people need us than ever.

Thank you to our PF Awareness Month 2024 sponsor, Trevi Therapeutics

By setting personal challenges, and taking part in our Go the Distance and Create a Stir challenges, our incredible community **raised over £40,000** in September.

Our campaign 'Breathe' **helped over 97,000** people understand the difficulties of living with PF.

John Wringe, who worked in creative advertising and had PF, led the campaign's development. Sadly John died before the campaign could launch. Its success is a great legacy for him.

See the campaign at **bit.ly/breathecampaign**

As seen on BBC

PF Month featured on **BBC Breakfast TV** with Fiona, a mother who is living with PF and APF President Professor Gisli Jenkins. It was a fantastic way to launch our campaign nationally with **6 million viewers**.

Wendy Dickinson, leader of the Nottingham PF Support Group, received a surprise visit from **BBC's The One Show**, who featured her on 'The One Big Thank You'. And George from Devon spoke movingly about living with PF on **BBC Radio Cornwall**.

Thank you to Fiona and George for sharing their experiences to help others.

George and Angie

Fiona and Gisli at the BBC

Wendy on the One Show

Sign up to our newsletter to learn more about our work throughout the year and PF Month 2025. Visit **bit.ly/APFnewsletter** or click the button.

CLICK HERE

Life with PF symptoms

Lesley's story

How can you make the most of life while managing pulmonary fibrosis (PF) symptoms? Hear from Lesley about her experience.

Lesley, 74, from Felixstowe, had a persistent cough and breathlessness for around 18 months before she was diagnosed with idiopathic pulmonary fibrosis in 2020. She shares her story of how the sudden reality of her diagnosis made her want to take action.

When Lesley was diagnosed in 2020, she felt unclear about what her life would look like with PF – she'd never heard of it and was shocked to learn that it would be life-limiting.

'At first, it didn't progress much; my test results would come back reasonably okay, but it has taken a significant dip in the last six months. It was at that point I truly began to understand the challenges of living with PF.

'I thought, "No, no, this is a disease that's not going to get me. It might be life-limiting, but not with me." I was in a bit of denial.'

Knowing how PF can impact someone's life, Lesley is determined to help others affected by PF in any way she can.

'I can't tell you how important it is to me to spread awareness. I don't want this to happen to other people if it can be prevented in the future. My friends and family are passionate about raising awareness too. They really are doing everything they can, and I find that so heartwarming.'

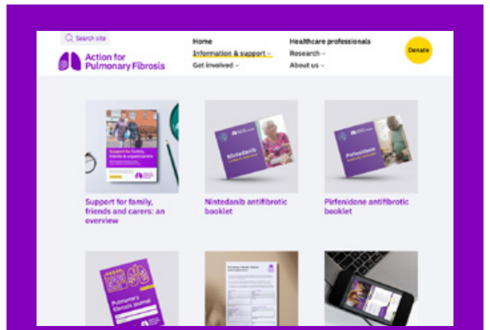
Lesley has started a support group in Ipswich for people affected by PF. They meet once a month for a coffee and a chat.

'The people I've met have made my life more positive. We all come from different walks of life, and many of us struggle in different ways, but we all support each other. The people I've met have inspired me.

'Being faced with your own mortality really makes you appreciate the positives of life. I try to live in the moment and make the most of every day. I make the effort to enjoy all the things I can do, and I don't dwell on the things I can no longer do.'

If you or a loved one is coming to terms with a diagnosis, you're not alone. Action for Pulmonary Fibrosis is here for you. Call our Support line on **01223 785725** or email **supportline@actionpf.org**.

Find out more about living well with pulmonary fibrosis



Booklets and web pages

We offer information on all aspects of living with pulmonary fibrosis (PF), from diagnosis to travel, and mental health to vaccinations. You can read web pages, order printed booklets, or print at home at **actionpf.org**

You can also order printed copies of booklets or web pages by calling **01733 839642**.

We offer translations of some of our resources, and we can often translate on demand. Please get in touch if you're interested in this.

Webinars

Join our live online events, where you can hear directly from professionals and people affected by PF, and have your questions answered.

'The most positive day I've had since being diagnosed.'

Book your place on upcoming webinars or watch previous recordings at **actionpf.org/information-and-support/webinars**

Have you or a loved one been recently diagnosed?

Being told you have PF can be overwhelming. There can be a lot of information to take in, practical things to think about, alongside lots of different emotions.

Our recently diagnosed information pack introduces you to what you might want to know about PF, without adding to the overwhelm. It can help you to:

- Get the most from your appointments, knowing what questions to ask and what to expect
- Have your early questions answered and know where to go for more information when you're ready
- Know where to get support

'It covers such a lot. I think it's fantastic.'

'I have never seen anything as structured as this which provides such a relevant insight... invaluable.'

View and order online at **bit.ly/RDpack** or order by phone on **01733 839642**.

The information pack is also available in Urdu and Welsh.

Healthcare professionals can fill in our quick online referral form at **bit.ly/APFreferral** to send a pack directly to your patients.

Help shape our information

You could join our Information Guidance Group to review information resources and help bring essential resources to the PF community.

Why is this important?

It's crucial that people affected by PF are involved in producing information to make sure it:

- Answers the questions people affected by PF would have
- Is relevant to people's experiences
- Is easy to read and understand
- Gets to the people who need it, when they need it

Who can get involved?

If you're affected by PF, get in touch to learn more about the role. You might have PF yourself or be a friend, family member or carer. You don't need to have an understanding of PF or any experience in creating information resources.

How do I find out more?

To join the Information Guidance Group, or to find out more, please email **involvement@actionpf.org** or call **01733 839642**.

Find all our resources on our website **actionpf.org**

Research

Making a breakthrough for PF

Did you know there is a worldwide community trying to make a breakthrough for people affected by pulmonary fibrosis (PF)?

Every day, people are working together to stop lives being lost to PF. During PF Month, people affected by PF, patient advocacy organisations like Action for Pulmonary Fibrosis, clinicians, researchers, pharmaceutical companies and technology developers came together at the European Respiratory Society Congress. There were over 20,000 delegates, all passionate about stopping respiratory disease.

Our CEO, Daniel Saxton, and Director of Research, Dr Wendy Adams, were there too. They learnt about the latest research and took part in crucial discussions about how we can ensure the voices of people affected by PF are at the centre of new research developments.

Daniel and Wendy at the European Respiratory Society Congress

What's happening in research?

- **New treatments:** Drugs are being developed to try to stop the lung scarring process.
- **New technologies:** Cutting-edge technology is being tested to allow earlier and accurate diagnosis. These technologies include wearables like smart watches to monitor symptoms and artificial intelligence to detect changes in images of the lungs.
- **New ways to receive care:** We're learning more about the importance of focusing on the needs of patients and their families. Monitoring health at home, access to nutritional support, and psychological support are just a few of the areas being researched.
- **Better understanding of the causes of PF:** New knowledge can help reduce the risks of developing the disease, for example, reducing exposure to toxic chemicals like silica dust.

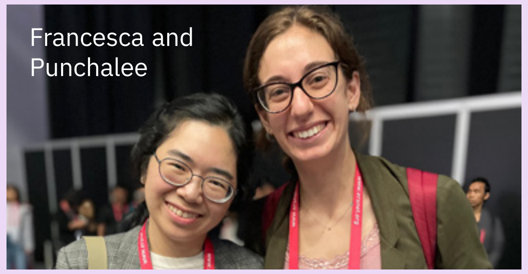
You can help us make a breakthrough

CLICK HERE

Donate now

Your donations help us support the next generation of exceptional researchers. This year, Dr Francesca Gonnelli, PhD Student (University of Nottingham) and Dr Punchalee Kaenmuang, Research Fellow (Imperial College London) and Clinical Observer (Royal Brompton Hospital) attended the European Respiratory Society Congress thanks to our Conference Awards.

Their research includes understanding differences in disease progression and the number of people affected by PF in Europe. By sharing their work with an international audience, they helped to raise awareness of the latest findings in PF, develop ideas for future research and encourage other researchers to get involved. **bit.ly/donateAPF**



Francesca and Punchalee

CLICK HERE

Take part in research

Ask your clinician about opportunities to take part in research or look at our online study finder. **bit.ly/APFstudyfinder**

Get involved

Use your voice to shape research.
Hear about opportunities to get involved:

Email **involvement@actionpf.org** or call us on **01733 839642** and ask for the involvement team to call you back.

Play to change lives!

Our weekly lottery is now live!

Not only could you **win £25,000**, by playing you'll also be helping us change the lives of people affected by pulmonary fibrosis through vital support and groundbreaking research. Win win!

Every ticket you buy truly does make a difference, so thank you!

If everyone who signs up to Insider magazine bought two tickets at £1 each, this would help us answer over 1,500 calls to our Support line.

Visit **bit.ly/APFlottery** or click the button to buy tickets or for more details.

CLICK HERE

Recognising excellent care

A huge congratulations to Natalie Waddington, Interstitial Lung Disease (ILD) Specialist Nurse at the Royal Lancaster Infirmary. Natalie was awarded the Patient-Nominated Award at the ILD-IN annual conference for going above and beyond for her patients and their families.

Thank you to the other nominees:

Janine Hood; Exeter ILD team; Jennifer Lynch-Wilson; Tom Linesâ; Sarah Lines; Tom Lines; Huzaifa Adamali; ILD Team at Churchill Hospital (Oxford); Bristol ILD team; Natalie Murray; Dr N. Weatherley and ILD Nurses team; Bristol ILD team; Lisa Green; Matt Wells; Dr Peter Saunders; MCH Respiratory Team; Louise Newman.

Natalie

Natalie and our CEO Dan Saxton

'I feel very proud and honoured to receive this award. I'm very lucky that I work within an amazing team and have excellent support from community teams to ensure that patients feel well educated/supported. I feel it's a privilege to be part of the ILD patients/families' journey.'

APF is here for everyone affected by pulmonary fibrosis who needs information, support, or a listening ear. Donate today by visiting **bit.ly/donateAPF** or click the button.

CLICK HERE

Time to celebrate

Celebrations and events

Winter brings lots of celebrations and events. How can people with pulmonary fibrosis (PF) make the most of the season?

From Diwali to Christmas, Hanukkah to Chinese New Year, there are lots of celebrations this season to distract us from the long nights and cold weather of winter.

Parties, gatherings and events can be tricky to navigate for people with PF. But while dancing all night may be off the cards, it's still possible to enjoy these events. Here are our tips to help you make the most of the winter celebrations coming up:

Plan ahead, ask for help

If you're anxious about attending an event, try thinking through exactly why, what would make it easier, and who can help with this. Remember: people will almost certainly want to help you feel comfortable. You just need to let them know what you need.

For example, if you're worried there won't be enough seats at a party, why not ask the host if they can make sure you have one? Worried you won't be able to manage a big, rich meal at a dinner? Speak to the organiser in advance to ask for a smaller portion or different dish.


Frank Bigley

Managing your symptoms

Persistent coughing can be difficult to deal with when you're in a crowd. It can feel disruptive, and you might feel anxious about being unable to stop. Don't be afraid to explain to people that coughing is a symptom of your PF. And make sure you have water to hand, and lozenges or chewing gum if they work for you.

You could also look for a quiet area you can retreat to so you can get your coughing under control. Taking some time out can help with tiredness and breathlessness too.

> *'When I see my friends, it's not always the time or place to give them the details of how I'm doing. To save some awkwardness, I've started sending regular updates on Facebook or via email. Then they know exactly what's going on and we can just have a quick catch up about it before talking about other things.*
>
> *'It also gives me a break from it. I can just have a meal and a glass of wine and let go of the disease for an hour or two. It doesn't feel classy, sending updates on Facebook, but it works for me!'*
>
> **Frank Bigley**

Prepare for going outside

Do you have any outside events planned? Cold air can tighten your airways, making it harder to breathe. Using your reliever inhaler half an hour before going out can help. And drinking warm water when you come back indoors from the cold can reduce any burning sensation in your lungs.

If you have one, try to your keep oxygen cannula tucked inside your clothes to stop it stiffening or splitting in the cold too.

Stay safe

Socialising more, especially in winter, can increase your risk of catching a respiratory infection, which can make your PF symptoms worse. Make sure your flu and Covid-19 jabs are up-to-date. Ask your GP about the pneumonia and shingles vaccines too.

A worthwhile effort

Going to celebrations and events can seem daunting. It may be tempting to avoid them altogether. But remember that connecting with your friends and family and having a good time together is important for your wellbeing. So do think about taking part if you can.

Share advice

How do others manage celebrations and events? Join one of our support groups to chat through this and more with people who really understand. Find your local group by clicking the button or visiting **bit.ly/findasupportgroup**

CLICK HERE

Support for carers

Carer's assessments

Caring for someone with pulmonary fibrosis (PF) can be rewarding, but challenging too. A free carer's assessment from your local council can help you organise any support you need.

What's a carer's assessment? Why should I get one?

A carer's assessment looks at how caring impacts you physically, mentally and practically, and what help is available for you.

It's all about making sure you have the support you need if you're looking after someone with PF. It isn't a test of your caring abilities.

Depending on your situation, a carer's assessment might lead to your local council offering you support such as:

- **Someone to take over caring so you can have a break**
- **Help with housework and gardening**
- **Help with travel costs**
- **Equipment or home adaptations**
- **Training on how to lift safely**
- **Gym memberships and exercise classes to relieve stress**
- **Benefits advice**
- **Putting you in touch with local support groups**

Even if you don't have any difficulties with caring, a carer's assessment can help you plan for the future. For example, it can help you decide what to do if you fall ill and can't care.

Who can ask for a carer's assessment?

Anyone over 18 who cares for someone can have a free carer's assessment. If you're looking after someone regularly because they're ill, older or disabled, you count as a carer, even if you don't call yourself this.

Carers might help with washing, dressing, taking medicine, shopping, housework, getting out, going to appointments, paying bills and giving emotional support and company. You might help with all these or just a few.

What does a carer's assessment involve?

Carer's assessments are usually face-to-face and take at least an hour. Some councils do them over the phone or online.

During the assessment, you'll talk to someone from the council, or an organisation the council works with, about how caring affects your physical and mental health and your social, family and work life. The assessor will also ask about any support you have and what support you'd like.

How do I get a carer's assessment?

Social services commissions different organisations to carry out carer's assessments. Enter your postcode on the Carers Trust website **bit.ly/Carers-Trust**, or scan the QR code below to find a local service that carries out carer's assessments.

Do you have any questions about carer's assessments?
Call our Support line on **01223 785725** or email **supportline@actionpf.org**

CLICK HERE

Fundraising stories

A lobster tribute

Action for Pulmonary Fibrosis (APF) fundraisers are always coming up with creative and unique ways of raising money to support our work. Jan Bulley and her friends recently organised a lobster-themed tribute to their dear friend, Bridget, raising vital funds for APF.

Jan thought it would be a nice idea to sell small lobsters and refreshments to raise money. The event was a huge success, making £1,400!

'APF was Bridget's chosen charity, and it needs funds for research and to support and help others. I felt that our efforts would be a loving tribute to Bridget's memory,' said Jan.

If you'd like to host your own event for APF, Andy Bright, our Community Fundraising Officer, would love to hear from you. You can email him on **andy@actionpf.org** or call him on **07508 857146**.

Festive fundraising for APF

It's beginning to look a lot like Christmas here at APF! With the festive season on our doorstep, what better time to get creative with your fundraising. Whether you're fundraising at school or with family and friends, there are lots of ways you can get involved. Visit **bit.ly/fundraiseAPF** or click the button to find out more.

CLICK HERE

Walking 100km for APF

Go the Distance is a challenge where we invite supporters of all abilities to raise funds. Supporters set their own challenge and distance, and complete it in their own way, whether it's by running, walking, cycling or swimming.

After Fahmida's beloved mum, Sainoor Ismail, died from pulmonary fibrosis (PF) in 2023, she wanted to do something positive to help other people living with PF and raise funds towards APF research. So, Fahmida decided to take on our Go the Distance challenge! In August 2024, she walked a total of over 100km, in different places across the UK, completing the final part of her challenge in Eryri/Snowdonia. Not only did she surpass her 100km target, she also rounded up all her family and friends to join her along the way.

> 'My mum was the heart of our family, showing incredible strength and resilience even in her most challenging moments. I wanted to honour her memory by supporting those who are battling the same condition. By week two, I had already hit the 100km target, but I was determined to walk as much as I could and involve as many people as I could – whether in person or virtually, by video-calling friends across the globe as I walked.'

Fahmida raised an incredible £10,555 for APF and did a fantastic job of raising awareness during her walks too.

If you'd like to take on an amazing challenge for APF like Fahmida, you can find out more at **bit.ly/APFchallenges** or by clicking the button. We'll be there to support you every step of the way!

CLICK HERE

Behind the scenes

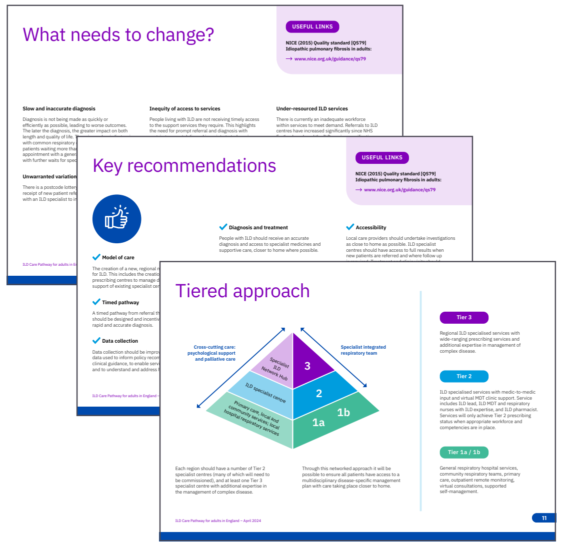
Improving interstitial lung disease services

Policy and Public Affairs

We're working across the UK to improve interstitial lung disease (ILD) services. We're building connections and supporting improvement which will help people living with pulmonary fibrosis (PF) now and in the future. Here are a few things we've been working on recently.

1 Applying the new care pathway

A new care pathway is guiding changes to ILD services across the UK. These changes will help people with PF access the care they need, closer to home. We're now piloting these changes in several areas of England, leading the way for nationwide change.



What needs to change?

USEFUL LINKS

NICE (2015) Quality standard [QS79] Idiopathic pulmonary fibrosis in adults:
→ www.nice.org.uk/guidance/qs79

Slow and inaccurate diagnosis

Diagnosis is not being made as quickly or efficiently as possible, leading to worse outcomes. The later the diagnosis, the greater impact on both length and quality of life.

Inequity of access to services

People living with ILD are not receiving timely access to the support services they require. This highlights the need for prompt referral and diagnosis with

Under-resourced ILD services

There is currently an inadequate workforce within services to meet demand. Referrals to ILD centres have increased significantly since NHS

Unwarranted variation

Key recommendations

USEFUL LINKS

NICE (2015) Quality standard [QS79] Idiopathic pulmonary fibrosis in adults:
→ www.nice.org.uk/guidance/qs79

✓ **Model of care**

✓ **Diagnosis and treatment**

People with ILD should receive an accurate diagnosis and access to specialist medicines and supportive care, closer to home where possible.

✓ **Accessibility**

Local care providers should undertake investigations as close to home as possible. ILD specialist centres should have access to full results when new patients are referred and where follow up

✓ **Timed pathway**

✓ **Data collection**

Tiered approach

Tier 3

Regional ILD specialised services with wide-ranging prescribing services and additional expertise in management of complex disease.

Tier 2

ILD specialised services with medic-to-medic input and virtual MDT clinic support. Service includes ILD lead, ILD MDT and respiratory nurses with ILD expertise, and ILD pharmacist. Services will only achieve Tier 2 prescribing status when appropriate workforce and competencies are in place.

Tier 1a / 1b

General respiratory hospital services, community respiratory teams, primary care, outpatient remote monitoring, virtual consultations, supported self-management.

Each region should have a number of Tier 2 specialist centres (many of which will need to be commissioned), and at least one Tier 3 specialist centre with additional expertise in the management of complex disease.

Through this networked approach it will be possible to ensure all patients have access to a multidisciplinary disease-specific management plan with care taking place closer to home.

ILD Care Pathway for adults in England – April 2024

11

2 Spreading the word about PF

We brought the voices of lived experience to ILD and respiratory conferences across the UK. At the Boehringer Ingelheim ILD Academy in September, we came together with charities, healthcare professionals and other organisations in practical workshops. In one workshop, we discussed how each healthcare professional could help to bring the new care pathway to their service.

L-R: Barbara Taylor (Patient Engagement Lead at Boehringer Ingelheim), Lisa Murray (Policy and Public Affairs Officer at Action for Pulmonary Fibrosis (APF)), Ailsa Bosworth MBE (Patient Champion and Founder of National Rheumatoid Arthritis Society) and Vani Manja (Managing Director and Head of Human Pharma for Boehringer Ingelheim UK and Ireland)

3 Making sure people affected by PF are heard

We've formed the OneVoiceILD Steering Group and Lived Experience Panel. Both groups include people affected by PF, and their input will guide our work.

The insights from people affected by PF ensure that everything we do is focused on improving the lives of people affected by PF.

4 Putting PF on the new parliament's agenda

The government is conducting an independent investigation into NHS performance. As part of this, they want to hear about people's experiences of the NHS. We used this opportunity to bring attention to ILD services, sharing stories from people affected by PF.

What is OneVoiceILD?

#OneVoiceILD is a growing network that is striving to improve treatment, care and support for people affected by PF. We're taking a stand to make sure that everyone with PF in the UK gets faster diagnosis, better access to treatment, and the support they deserve, no matter where they live.

What is interstitial lung disease (ILD)?

A group of diseases that affect the interstitium. The interstitium is the space in the lungs between the air sacs and the blood vessels. PF (lung scarring) is a part of many ILDs.

5 Transforming ILD services in Scotland, Wales and Northern Ireland

APF, healthcare professionals, and people affected by PF came together to design a new pathway for ILD care in Northern Ireland. Data helped us understand where services can be improved – for example, knowing how many people with PF are in each area, so centres can plan staffing levels and the number of appointment slots. This will reduce waiting times.

'Healthcare professionals and patients in Northern Ireland have joined forces. We're ensuring every person diagnosed with ILD is diagnosed at the earliest opportunity and has equal access to holistic care.'

Nazia Chaudhuri, Respiratory Medicine Consultant

We presented our care pathway work to the Cross-Party Group for Lung Health at the Welsh parliament (Senedd Cymru). We are now working with the NHS Wales Executive to improve outcomes for people with ILD in Wales.

We've offered our support to make the Respiratory Action Plan a reality, to improve ILD services across Scotland.

6 Spreading the word about PF

We're now a formal member of eight groups working to improve respiratory care in the UK. These groups are made up of UK respiratory charities and organisations, and by adding the voices of people with PF, we'll make sure PF is not left behind.

Your voice is needed more than ever.

Don't miss future opportunities to get involved by telling your story, signing petitions and more.

ONE VOICE ILD

Help us transform PF care by:

- Following us on social media **#OneVoiceILD**
- Signing up for our e-newsletter at **bit.ly/APFnewsletter**
- Emailing **OVILD@actionpf.org**, or calling **01733 839642** to see how you can get involved

CLICK HERE

All about oxygen

Q&A with Jo Dallas

Our Senior Interstitial Lung Disease (ILD) Nurse, Jo Dallas, answers the most common questions she hears from people with pulmonary fibrosis (PF) about using oxygen.

'After 20 years working in ILD within the NHS, I joined Action for Pulmonary Fibrosis (APF) in July 2024. As a Senior ILD Nurse at APF, I help people living with PF access the care and support they need, answer queries on our Support line, and help to create our information and education resources. Your generous donations made my role possible, so thank you!'

Jo Dallas

Top tip

Never buy oxygen online or without a prescription – using the wrong amounts can cause damage to your brain, heart and lungs, and even death.

What's the difference between ambulatory and long-term oxygen?

'Ambulatory' oxygen is portable oxygen that can help you breathe more easily when you exert yourself (by walking, for example). It comes in small cylinders you can take outside your home.

If you need more than ambulatory oxygen, long-term oxygen therapy (LTOT) may help. For LTOT, you'll need to have an oxygen concentrator installed in your home. Your doctor will give you a prescription telling you how many hours a day you should use this oxygen.

Some people have both ambulatory oxygen and LTOT. You can use your oxygen concentrator at home and then take ambulatory oxygen out with you.

Does oxygen cure breathlessness?

Using oxygen helps many people with PF feel less breathless. But, unfortunately, it's not a cure and won't take breathlessness away completely.

Top tip

Oxygen can dry out your skin, so use water-based creams to keep moisturised. Avoid moisturisers with paraffin, it's flammable!

Can I use oxygen before and after I go out, rather than taking it with me?

I wouldn't recommend this. If you need oxygen while you're out, perhaps to take part in activities or exercise, you'll need to use it as you do these things to feel the benefit. The oxygen we breathe in only stays in our bloodstream for a short time – you can't 'build it up' for later use.

My portable oxygen equipment feels heavy. Is there a lighter version?

Unfortunately not. A battery has to weigh a lot for a high flow rate and long delivery time. We don't yet have a lightweight version.

> *'I've got no problem walking into a restaurant or public place with my oxygen. I need it. I've got this disease and there's no getting away from it. This is who I am. If I had broken a leg and walked in with a crutch, it's the same thing really, isn't it?'*
>
> **Hilary, Southampton**

I take oxygen in my car. Do I need to do anything?

Oxygen is flammable, so make sure it's secure and can't roll around. Keep the equipment upright. In case you're in an accident, put a sticker on your car saying you're carrying oxygen, so the emergency services can take precautions.

Finally, tell your car insurance provider. This shouldn't affect your premium, but it will make sure you're fully covered if you need to make a claim.

> *'Since I've been on ambulatory oxygen my cough has decreased enormously. I try to walk at least two miles a day. Oxygen is giving me the freedom to be out in the fresh air.'*
>
> **Christine, Lincolnshire**

My pulse oximeter says 50% but I feel fine. Should I go to hospital?

Pulse oximeters (small devices you can attach to your fingertip to test how much oxygen is in your blood) for use at home aren't always accurate. It depends on the quality of the device, your blood thickness, heart rate and more.

If you feel fine but are getting unusually low oximeter readings, it's likely due to one of these issues.

However, if you feel unwell in any way and your blood oxygen saturation levels are falling, you should seek medical help.

Top tip

If your nasal cannula causes sores behind your ears, ask your healthcare team to add Easy Wrap pads to your prescription.

Any questions?

CLICK HERE

Remember, this article only answers some commonly asked questions. It isn't a complete guide to using oxygen. Your medical team or oxygen supplier is on hand for any questions you have, and you should always follow their advice.

You can also find out more about oxygen – including using it while travelling – at **actionpf.org** or by calling our Support line on **01223 785725**.

‘Give it a go’

Hilary, 71, from Southampton, talks to Insider about her unexpected oxygen prescription and finding what helps her to live well.

I was going about my business as normal, then all of a sudden, I’m being told I need ambulatory oxygen.

I thought I just needed it when I exercised or did something strenuous. But to the medical professionals, it’s more than that.

There is a little bit of denial in me but I find this helps me to carry on doing the things I want to do while still being sensible. For example, I went to a local food festival on a hot day in the summer. I know hot weather makes things a bit more difficult for me so I was more careful, but I still went and enjoyed myself.

Paul, my husband, worries about me using oxygen. I think to him it’s a sign of weakness in some ways. I reassure him that it’s not, it’s allowing me to do what I want to without any problems, and he understands that.

I’m willing to try new things and I think that’s helped me stay positive.

Give it a go, I say. It might not be for you, but no harm in trying.

I wasn’t sure about pulmonary rehabilitation, but it literally changed my life. It gave me the confidence to exercise and to get breathless. They explained a lot of the medical stuff too, which was helpful because I like to understand why things are changing. If I understand then I can cope. If I don’t understand why things are happening then that’s scary. The sessions really turned my attitude to the disease around and made me a lot more positive.

You can go down a bit of a rabbit hole on the internet.

It’s easy to get caught up in problems that you don’t have, and there can be a lot of negativity or things that aren’t terribly useful. It doesn’t do you a lot of good to read too much about that.

> *‘I find that I’ve got to be reasonable in my expectations when looking for information. I’m not going to find a magic answer.’*

You’ve also got to know your own capabilities and limitations. Everyone is different so you’ve got to look for a different way around things that works for you.

Ask your healthcare team for a referral to pulmonary rehabilitation.

Call our Support line team on 01223 785725 for trusted information and signposting to helpful services.

Donate so we can be there for everyone affected by pulmonary fibrosis.
Click the button to make a difference!

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Action for
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