

Insider

Living well with pulmonary fibrosis

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Spring/Summer 2024



Action for
Pulmonary
Fibrosis

actionpf.org

Hello from Mike...

Dr Michael Stubbins, who became chair of our board in November, introduces himself and explains his hopes and priorities for Action for Pulmonary Fibrosis (APF).



I'm a passionate advocate for people affected by pulmonary fibrosis (PF), so I'm pleased to be taking the reins as chair at such a pivotal time for APF.

I've experienced first-hand how this disease can devastate the lives of those affected. My mum had idiopathic pulmonary fibrosis (IPF) for over 10 years. I witnessed her struggling to get a diagnosis, which was far from straightforward. And then I watched her struggle to live with the disease. It sounds funny saying it, but looking back and now knowing more about IPF and other PF diseases, Mum was one of the lucky ones – she got quite a long time with a relatively slow decline in lung function until the last couple of years. But it was still very hard for her and for us as her family.

With Mum's experiences in mind, I'd like to push forward APF's work to support people with PF to live well. We need to make our services for patients and families better, and reach more people with our local groups, Support line and more. We already know that certain segments of the patient community don't tend to come forward. We want to make sure we fully understand why, and that we're doing everything possible to make ourselves accessible to all. We also want to make sure we continue to push the NHS to create an effective care pathway for interstitial lung disease.

In my professional career I'm a scientific researcher and I worked for a pharmaceutical company for most of my career. I wanted to get

involved with APF because I knew PF research – let alone finding new drugs – was slow. It just felt to me that we could do more. APF has just awarded two significant research fellowships, and it's vital we raise more funding to make more research breakthroughs.

Thanks to the staff team for their warm welcome to me as chair, and of course to everyone who donates to, volunteers for or supports APF. We've done extraordinarily well to weather the economic storm and continue to grow. But we can't rest on that. Together, I know we can do more to make life better for everyone affected by PF.

Dr Mike Stubbins

Farewell and thank you, Lou!



After spending an incredible five and a half years leading APF as chief executive, Louise Wright has taken up the opportunity to become chief executive of Vista Blind, a sight loss charity in Leicestershire.

Recruitment for a new CEO is underway and we'll be making an announcement soon.

'It's been a privilege to be part of the lives of people with PF. I'm looking forward to watching APF go from strength to strength.'

Louise Wright, departing CEO

PF month 2024

Pulmonary Fibrosis Awareness Month SEPT 2024

Will you help us **Create a Stir** this September?

Bring your family, friends and loved ones together for our annual Pulmonary Fibrosis (PF) Awareness Month in September 2024 by hosting a **Create a Stir coffee morning**. Share delicious food and drink with your loved ones to spread the word of PF and raise vital funds. Create a Stir brings hundreds of people together from across the UK. We'd love you to get involved this PF Awareness Month.



[Read more >](#)

Create a Stir now by signing up for our free party pack. We'll be there to help you every step of the way. Simply register online at actionpf.org/create-a-stir or by scanning the QR code. Or you can call us on 01733 839642 if you prefer.



Coming together across the world to mark PF Awareness Month

Our annual Awareness Month in September is our chance to join in with countries across the globe so that more people know about the devastating effects of PF. We can bring people together to positively change the lives of people affected.

In 2023, tens of thousands of people heard about PF for the first time thanks to our 'Hear my lungs' campaign. The powerful message was seen on billboards across the UK, and shared by celebrity Katie Price and her mum, Amy Price, who is living with PF.

This year, we're responding to your insights that people are finding out they have PF too late. To ensure people get diagnosed sooner, we're raising vital funds so we can continue our work, and equipping the PF community with resources to raise awareness. With your help, we can be there for everyone who needs us.



Life with PF symptoms

How can you make the most of life while managing pulmonary fibrosis (PF) symptoms? Hear from Seema and Malcolm about their experiences.

Seema

Seema, from London, cares for her dad, Peter*, who was diagnosed with idiopathic pulmonary fibrosis two years ago. Seema helps Peter live life with PF to the fullest.

We stay positive but realistic

Yes, he's got this disease, and he knows it's going to progress. But we try not to let it take over everything. I don't want him to be left thinking "my life's over" because it's not. You need to make use of the time you've got and enjoy it. We help him stay mentally strong and active.

Finding the right info is so important

There's information out there and we've found what works for Dad. Listen to people's experiences and learn from one another.

What really helped was APF's online event about living with PF. There were doctors talking about research and people with PF talking about their experiences. I was writing notes the whole time.

→ See upcoming free webinars or watch recordings of past events at bit.ly/apfwebinars



[View more >](#)

Pulmonary rehab helps Dad stay active

Dad absolutely loved doing pulmonary rehab last year. And he's carried on with the exercises. There was also a social side, too, as he could interact with people and hear their experiences.



Dad's always loved cooking

When he started taking medication, Dad was off his food and felt nauseous. It took a while to settle down but we're able to manage it now.

For ages, he didn't like the smell of certain foods, so didn't cook. But more recently, he's got back into it.

→ Are you unsure about your diet or how to manage changes to your appetite? Ask your healthcare team about a referral to a dietitian.

We needed some reassurance

I found exercises on the internet for Dad, but I was nervous for him to try them. I didn't know what his oxygen levels or pulse needed to be or how to tell if he was doing it right. We saw a respiratory nurse who showed us what to do, which really gave him confidence.

Carers: look after yourselves too

Find as much information as you can, but don't just use Google. Speak to experts and hear about people's experiences. For me, writing down what I need to do for my dad helps a lot. I do this once a week and it helps me switch off.

*Names changed for confidentiality

Malcolm

Malcolm Dawson, 73, lives in Worcestershire with his wife, Elizabeth. He was diagnosed with progressive PF in 2022.

Back in the day, I was lead singer in a band and I still sing now with my group, The Wheely Different Theatre Company. I sang solo in a recent show, which sold 150 tickets! I have my oxygen on while I sing. I like to stand up and sing, so I make sure to sit down as soon as I finish.

I've got a mobility scooter and that's lovely. It's great to be able to drive around and get some fresh air.

I still drive, but my car's parked up a steep gradient. I take my portable oxygen machine, stop after a few yards, allow my oxygen to build up, and then start walking again.

I recently got a stairlift, which makes a fantastic difference. I've lived in my house for 28 years, and I didn't want to move. However, climbing the stairs left me so out of breath. I got my stairlift and scooter from the Pulmonary Fibrosis Trust.

→ Contact our friends at the Pulmonary Fibrosis Trust to find out if you're eligible for equipment funding. Call **01543 442191** or visit bit.ly/equipmentfunding

I still do some gardening, too. I've got a show garden – people come from all over the country to see it. It was even on a TV programme with Sheila Hancock. I tend to do just five minutes at a time, and I'm fortunate the lady next door helps me.

It can be frustrating. With the gardening, for example, I used to do 30 hanging baskets a day, now I might do four. The mind still wants to, but the body just doesn't let me.

I have to knuckle down and think "OK, today's not going to be such a good day. We'll just take it a bit steadier". But the way I look at it is, if I wake up in the morning, we can deal with the rest of the day.



Malcolm and his wife, Elizabeth



Malcolm performing



Singing is one of Malcolm's passions

Find out more about managing symptoms and living well on our website, actionpf.org, or call our Support line on **01223 785725**.

Transforming PF care

Healthcare pathway

Thanks to your feedback, we've developed detailed guidance on what the best care should look like for people with pulmonary fibrosis (PF). We're already working with several healthcare providers to trial the new guidance and transform their services for the better.

Last year over 1,000 of you told us about your experiences of PF care through our survey. Your insights emphasised that the current care pathway for interstitial lung disease is simply not fit for purpose. Urgent change is needed.

Taking action

In response to the survey, our OneVoiceILD movement brought together a group of people with lived experience and healthcare professionals to develop a vision for the future of care. This is the newly launched ILD care pathway. It gives healthcare professionals step-by-step guidance on what best PF care should look like.

We're now supporting several areas in England to pilot the pathway and improve their services to meet PF needs. We're working with those in the devolved nations to see how this could be adapted for their health systems.



A 'care pathway' is the specific journey a person with PF takes through the healthcare system, from suspecting they might have PF to receiving a diagnosis, treatment, and potential lung transplant.

Lynne, whose husband Chris has PF, explains why the current system must change:

'Our friend was diagnosed with cancer last year and was told to bring their partner with them to receive the news. They went away with almost too much information and lots of resources for support. Chris wasn't allowed to take anyone and came away with absolutely nothing.'

Chris hasn't had the same follow-up as others have. We think our location might be part of it. The consultant is 90 miles away. We have local care, but they're understaffed and overwhelmed. Chris hasn't had a regular review in two years.'

We need the system to change. I don't want anyone to have the same experience we have.'

Chris and Lynne in 2021, whilst Chris was awaiting a diagnosis



Here are just a few examples of challenges you told us about in the survey, and how the new care pathway will help:

Health professionals didn't communicate clearly with me about my condition.

Healthcare professionals will have a better understanding of the care, treatment and support required by people with PF. They will also be required to provide a care and treatment plan when you're diagnosed.

I had to wait a long time to be diagnosed, which affected my health and wellbeing.

The new pathway suggests introducing timelines for diagnosis and start of treatment. We hope that this will be the first step towards PF being treated with the same urgency as cancer.

I can't access all the care I need in my area.

The pathway directly supports service providers to increase specialist staff and PF expertise. This means more areas can provide specialist care, including antifibrotic drugs.

Does a member of your ILD team deserve recognition?

Interstitial lung disease (ILD) healthcare professionals go above and beyond to support, care for and treat people affected by PF. We're working in partnership with the healthcare professional association ILD-Interdisciplinary Network (ILD-IN) to give you the opportunity to nominate an individual or team for an award!



Nominate online by scanning the QR code here or make a phone nomination by calling 01733 839642.

Voting closes 2 September 2024.

Vote now >



Have your say! If you'd like to hear more or get involved with OneVoiceILD, visit our website or get in touch at ovild@actionpf.org

The need for APF is greater than ever

As people face longer delays in receiving specialist care, our services have seen a spike in demand in recent months. Can you help us continue our work?



In the last issue of Insider, you may have read about the key findings in our survey, 'I wish it was cancer'. The survey found that:

Nearly

50%

of people diagnosed with pulmonary fibrosis (PF) were not signposted to information and advice services or support

Nearly

50%

said they can't always get hold of a specialist nurse when needed

Almost

90%

have not received mental health support since diagnosis

We supported 60% more people in January 2024 than a year ago. Not only that, calls to the Support line last year increased fourfold compared to 2021/2022. And 20,000 people each month are accessing vital information on our website to support their wellbeing.

The need for APF is greater than ever before.

Our services are adapting to meet the needs of around 70,000 people in the UK living with PF. We are recruiting a specialist nurse as part of the APF team who will advise and advocate for the PF community, and our Support line is there for everyone affected by PF, providing practical advice and support.

You can help us continue our work.

Donate to help us be there for everyone affected by PF. You can give at actionpf.org/get-involved/donate

'I'm extremely grateful for all the support, advice and patience given to me. The service offers hope at a time of great difficulty. Cannot thank you enough.'

An APF Support line user



→ Read the full survey report at bit.ly/APFsurveyreport

Pulmonary fibrosis risk factors at work: What can I do?

Current research tells us there is no single cause of pulmonary fibrosis (PF). Instead, there are different risk factors. Breathing in dust, fumes or mould can be a risk factor, and some people are exposed to these at work.



Oliver Collett, Irwin Mitchell Solicitors

Dust, fumes and mould can come from substances including:

- Asbestos
- Silica (found in the dust of rocks, clay and sand)
- Wood/coal
- Bird feathers/droppings
- Moulds
- Metalworking fluids

Breathing in these substances over a long period of time might be a risk

factor for PF. But this alone isn't enough to develop the disease. If it were, everyone working in these environments would have PF, whereas only some people do.

It's thought that people with PF have a combination of risk factors. Other risk factors for PF include:

- Ageing
- Family history (the genes inherited from your parents)
- Other conditions, such as rheumatoid arthritis

Reducing your risk factors at work

If you work with hazardous substances, including dust, fumes or mould, your employer must provide personal protective equipment. If your work has an occupational health team, you could talk to them about potential exposures at work.

The Health and Safety Executive ([hse.gov.uk](https://www.hse.gov.uk)) has information on ensuring your safety at work.

Claiming compensation

If you have PF and think it may be linked to exposure at work, you may be able to claim compensation. We spoke to Oliver Collett, Partner, Asbestos & Occupational Disease, at Irwin Mitchell solicitors, about claiming compensation.

How can compensation help?

Your settlement could help fund any care you need, plus pay for specialist private medical treatment, loss of earnings and expenses like travel costs.

How much will it cost?

Many law firms can pursue your case on a no-win, no-fee basis. This means you don't need to pay any money upfront. And if your claim isn't successful, you won't have to pay any legal fees.

How long do I have to claim?

You usually have three years to make a claim from the date you were diagnosed with a work-related disease. If you want to claim on behalf of a loved one who has passed away because of their lung disease, you'll have three years from the date of their death.

Can I claim if my employer is no longer trading?

Possibly. Lawyers can trace the company and check whether it's currently trading under a different name. If your employer is no longer trading, don't worry, as compensation is usually paid by your former employer's insurer. Even if you were exposed decades ago, lawyers may still be able to find who was responsible so you can access the compensation you deserve.

Find a solicitor using the Association of Personal Injury Lawyers by visiting apil.org.uk or calling **0115 943 5400**. Please note that APF does not endorse or recommend any law firm. We recommend speaking to a few before making a choice.

Antifibrotics



Your questions answered

Abdallah Alkhalaf, specialist clinical pharmacist in respiratory medicine at Nottingham University Hospital, explains what you need to know about the medications available to slow pulmonary fibrosis (PF).



What are antifibrotics? How can they help with PF?

Antifibrotic medications like pirfenidone and nintedanib can slow down the rate of scarring in your lungs. This may reduce the rate your PF progresses. However, antifibrotics don't stop lung scarring completely or get rid of any scar tissue that has already formed.

Pirfenidone and nintedanib are currently the only antifibrotic medications available in the UK to treat different types of PF.

Who can take antifibrotics?

People with various types of PF may be able to use nintedanib. Pirfenidone can only be used if you have a particular type of PF called idiopathic pulmonary fibrosis (IPF). To assess your eligibility for antifibrotics, your doctor may request a lung

function test (breathing test) as well as perform other tests required. Your ILD team will be able to talk through whether antifibrotic medicines might be suitable for you.

What's the difference between nintedanib and pirfenidone?

There are several differences between nintedanib and pirfenidone such as how often you take them, the way they work and eligibility criteria. While neither medication is recommended over the other, one may work better for you.

Your doctor will look at several factors when deciding which antifibrotic medication to prescribe, including your type of PF, eligibility criteria, other medical conditions or allergies, and other medication you are on.

What are the side effects?

Some common side effects of both medicines can include diarrhoea, vomiting, stomach pain, weight loss and headaches. Pirfenidone can also make your skin more sensitive to sunlight. Your ILD team will help you manage these. Some side effects will get better over time.

Find out more information about antifibrotics at bit.ly/antifibrotics



Fundraising stories



Young supporter Margot at Amanda's crafty fundraiser



Andreas Zacharia and Rozalinde Paul during the London to Brighton Cycle Ride 2023

Crafting in the community

After Amanda lost her beloved mum to pulmonary fibrosis (PF), she wanted to give something back to the community. She not only volunteers as an APF telephone befriender but has also used her talent for crafting to raise vital funds for APF.

'When Mum died, I found lots of craft stuff. I attended a sewing class to learn how to craft and made things to sell in Mum's memory, just in time for Mother's Day.'

Amanda's unique handmade crafts raised a fantastic £670 for APF. As a charity that receives no government funding, we really do rely on our incredible supporters like Amanda. They make it possible for us to run services like telephone befriending. This service brings life-changing support and companionship to people affected by PF.

How could you fundraise?

Whatever your interest or talent, you can help us to support people affected by PF.



A whizz in the kitchen?
You could host a bake sale.



Love bringing people together?
You could put on a quiz night.



An eye for a bargain? You could organise a raffle or auction.

London to Brighton

Date: Sunday 15 September
Location: Clapham Common – Brighton Seafront
Fundraising pledge: £300

Take on the iconic 55-mile London to Brighton Cycle Ride this September and do something amazing for APF! Starting in London, and finishing in scenic Brighton, this ride is perfect for all abilities of cyclist. We will be there to support you all the way with fundraising packs, T-shirts and tips on how to reach your fundraising goal. Places will fill up fast, so email us today to secure yours fundraising@actionpf.org

Every penny raised will help fund vital support and research for our PF community.

Giving in memory

Many people find comfort in remembering a loved one by supporting a charity close to their heart. A gift to APF celebrating the memory of someone special is a wonderful way to pay tribute to them.

You can help us continue to be there for everyone affected by PF by donating in memory actionpf.org/get-involved/donate

Read more >



For more information about fundraising in the community, please scan the QR code or visit our website at bit.ly/fundraiseAPF

Support groups

You aren't alone with PF

Pulmonary fibrosis (PF) support groups can be found across the UK, both online and in-person. The hard work of support groups means that communities of people affected by PF have a safe space to find reassurance, friendship and information. We asked people why support groups are important to them and tips for attending your first meeting.

East Lancashire Support Group:



Janine Hood, who started the group in 2015 Rugina Islam, who currently runs the group



'Support groups give you more confidence to talk about your illness.'

Kathleen, East Lancashire Support Group

'I joined the support group to meet people who had the same condition or cared for people with it. It's good because they understand how you feel and you can ask questions and get information on advice and help that is available. The social part is very important, it helps to put things in perspective.'

Member of Northamptonshire Support Group

'Living with any disease can be overwhelming. Living with PF is that much harder as there is little knowledge and awareness. This is why support groups are so important. They provide a safe haven for members to share common experiences and gain valuable resources and practical advice.'

'We want to let people know that PF does not define their life: they can take control, connect with others and empower themselves with the knowledge to continue living life on their own terms.'

Rugina Islam, East Lancashire Support Group

Taking the plunge: going to your first meeting



'New members are always welcomed at the door and introduced to other members. Any nerves would have disappeared very quickly after coffee and a good chat in the break, leaving you looking forward to the next session.'

'It can be daunting not knowing what to expect, but every member has been through this stage. My advice has always been to try before you decide as you may be pleasantly surprised. If it's not for you, at least you made an informed choice by giving it a chance.'

Rugina Islam, East Lancashire Support Group

'We learn so much from the speakers.'

Members of Northamptonshire Support Group

A shared space like no other

'It's a place for all of us to share our trials and tribulations and to support others with "What works for me may not work for you, but give it a go". It's also a place where you will be able to say what's on your mind without the fear of looking stupid. Your questions will be answered by those who already have the T-shirt. When I say "It's good to know I'm not alone" it's heartfelt, as although it's a group no one wants to be part of, at least we are a group of support with kindness and good advice.'

Huw Jones, Torbay Support Group



'Most support groups aren't run by APF, but we work in close partnership with many. APF is here to help your group thrive.'

Nicola Griffiths, Support Networks Manager

Most support groups welcome carers, friends and family at their meetings. APF also runs a monthly online support group specifically for carers, friends and family.

No support group in your area?

We can help bring together like-minded people and support your new group. Contact us on **01733 839642** to find out about grants, advice and the support group toolkit.

Read more >



Find your local support group by calling us on **01733 839642**, scanning the QR code or visiting our website at **bit.ly/findasupportgroup**

APF Research Study Finder

We are excited to announce the launch of our new Research Study Finder on our website. Don't have access to the internet? Ask your healthcare team about local opportunities to take part in research.

Want to know more about research?

Why is taking part in research important?

Scientists can learn a lot about pulmonary fibrosis (PF) in a laboratory, but they need help from people living with the disease to understand more. Taking part in research is a critical step in helping to:

- Understand the impact of PF
- Improve diagnosis and understanding of how PF changes over time
- Find new and better treatments

Research is important to lots of people affected by PF, but many people tell us they don't know what's happening or how they can take part. This is why we created the Study Finder.

What sort of things could I be asked to do?

There are lots of different types of research studies, so what you could be asked to do will vary. Studies could include:



One-off surveys:

Answer a set of questions online in less than an hour.



Clinical trials:

Help to learn more about potential new treatments, devices or interventions over several weeks or months. These often include medical assessments like breathing and blood tests.



A patient registry:

Agree to share some of your medical information to help scientists learn more about the disease over time.

What is the Study Finder?

The Study Finder is a web page where you can find information about different research studies taking place in the UK for people affected by PF. This includes studies that are currently looking for people to take part and results from studies that have already happened. We created the Study Finder by working alongside researchers and people affected by PF.



How do I use the Study Finder?

You can read about the exciting research that is happening now in the UK, read about opportunities to take part, or find out the results from recent studies. Visit actionpf.org/studyfinder or you can scan the QR code below. If you're interested in taking part, you can use the search functions to filter by the location, type of PF, travel requirements and whether the study is open to recruitment or upcoming.

If you want to find out more about taking part in a particular study, we encourage you to speak to your healthcare team about your interest. You may also be able to contact the research team directly, depending on the individual study. Each of the study pages has more information.

Can't see something that interests you? Check back soon as we often add new studies.

Can I find results about studies that have finished?

Yes, you can. Once a study is completed and the results are published, we will update information about what the researcher found and what the next steps might be.

What difference will the Study Finder make?

We created the Study Finder so that more people can find out what research is happening in the UK and how they can take part. We hope the Study Finder will help more patients and healthcare professionals get involved in research so that together as a community we can stop lives being lost to PF.

Read more >



Give the Study Finder a try to find out more about PF research and how you can take part – visit actionpf.org/studyfinder

Helping everyone to live well

Manisha Cook, a palliative physiotherapist at the Hospice of St Francis in Hertfordshire, explains the benefits of palliative care, no matter what stage your pulmonary fibrosis (PF) is at.



What is palliative care?

Palliative care helps people cope with the physical and emotional impact of living with a life-limiting condition, like PF. We support people at any stage of their illness, from diagnosis onwards. We include support for families too as we recognise the challenges of living alongside a person who has PF.

Palliative care is all about supporting people to lead a fulfilled and meaningful life.

This includes:



Managing physical symptoms



Emotional and spiritual support



Psychological support

We also recognise it's important to plan for the future and offer support to explore and discuss people's wishes.

Who provides it?

Lots of professionals provide palliative care, including:

- Doctors
- Nurses
- Social workers
- Family and wellbeing support professionals
- Occupational therapists

This support can take place in different settings including your home, local hospice or in a hospital.

Is it the same as end-of-life care?

No, it's not. End-of-life care is usually for people thought to be in their last year of life. Palliative care can last for much longer – sometimes many years. It can be an extra layer of support, advice and information.

How can palliative care help with PF?

Often, I find people who have benefited from palliative care become passionate about it. They want other people to know what a positive impact they have had from the support they've received. They're also keen to encourage others to not be afraid of accessing their local palliative support.

What does it involve?

People visit our hospice for a huge range of palliative care services from massage to fatigue management workshops. Our dedicated PF group at the Hospice of St Francis gives people a chance to support each other and share their stories.

People can also come to stay at our hospice for a few days, to receive support for symptoms like breathlessness. 60% of the people we admit only stay for a short time before going home. We're certainly not just a place for the final days of life.

How can I access palliative care?

Talk to your GP, consultant or specialist nurse about what's available in your area. You can often self-refer to your local hospice by visiting their website or calling them.

'I find it helpful to speak to other people with the same illness. You can get helpful tips for how to manage and cope. The staff are all very supportive too.'

Member of the Hospice of St Francis's PF group



Action for Pulmonary Fibrosis

Registered Charity SC050992 in Scotland
Registered Charity 1152399 in England & Wales

General enquiries:

01733 839642
info@actionpf.org

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

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