

Insider

Living well with Pulmonary Fibrosis

- ◆ Focus on exercise
- ◆ What we've learned from life with pulmonary fibrosis
- ◆ Your questions answered on oxygen
- ◆ Top 10 research priorities

Autumn/Winter 2022



Annie Scarfe



**Action for
Pulmonary Fibrosis**

www.actionpf.org

What's inside...

Welcome to our Autumn/Winter edition of Insider. We're delighted to welcome Lorna and Elaine to our Winter edition.

Meet our contributors:



Lorna Brown is the Physio Team Lead for Pulmonary Rehabilitation at Royal Papworth Hospital. Lorna set up Pulmonary Rehabilitation (PR) at Papworth Hospital in 1997. Today, most of Lorna's patients have fibrosis but she also sees a variety of other respiratory conditions. Lorna's passionate about Pulmonary Rehab and supporting people to live well with PF.



Elaine Kirby was diagnosed with IPF in her 50's. Elaine lives her life to the full and dedicates much of her time to supporting others. She's a Keep Fit Association seated exercise instructor and enjoys seeing the impact of exercise and dancing on people's wellbeing and health.



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Message from our Chair



As I'm writing this I can feel the seasons changing and I'm anticipating the winter months ahead. I know the cost of living crisis is dominant in all our lives right now as we think about keeping warm and healthy during the winter months.

When it's dark and cold I do sometimes get 'the blues'. We used to get out a lot to see friends and visit pubs, restaurants and theatres. But since Covid, getting about in winter has not been so easy.

I thought I'd share my three point plan to maintain my physical and mental health this winter:

Firstly, Hilary and I have decided that this winter we are going to see friends more – it's so important for our mental health. We will ask people to take lateral flow tests just before we meet and maybe leave a window slightly ajar to improve

ventilation. We will also get some heating for the garden so that we can invite neighbours in on an ad hoc basis. There is an element of risk in this bit we think it's a risk worth taking for our mental health.

Secondly, get out of the house and do some exercise every day – whether a walk or a short ride on my e-bike. Try and keep in condition since it improves breathing and makes you feel better. When I was very ill before my transplant and could not do much exercise, I would do pulmonary rehab exercises in our kitchen and we would go out for a drive every afternoon. Just getting out of the house is important.

Thirdly – I am going to try to put some structure into my day and do something special each day for me. I have friends who make wonderful crafts and others who go to the gym. My wife Hilary paints. Well, I have been failing to learn French for over 55 years, so I am going to dedicate 90 minutes every day this winter to

improving my French before we go on holiday next year! My last French teacher moved to the USA. I wonder if she would teach me over zoom...?

We are all different and assess risk differently but I hope each of you stays positive, strong and safe over the coming months. Please remember that APF is here to support you whenever you need.

Steve Jones



Action for Pulmonary Fibrosis is a patient-driven charity. Our vision is to find a cure for pulmonary fibrosis so everyone affected has a better future.

Here to help...

Visit our website and Coronavirus Hub:
www.actionpf.org

Contact our Support Team:
support@actionpf.org

Call our Support Line:
01223 785725



Wellbeing

Focus on exercise

Physiotherapist Lorna Brown talks to Insider about the benefits of Pulmonary Rehab and gives her tips for keeping active this winter.



What are the benefits of PR?

PR gives you the opportunity to ‘challenge’ your breathlessness in a controlled and safe way – whether that’s in person or online. Patients frequently tell me they come away feeling empowered to manage their condition better. They often learn as much from other patients with similar symptoms as they do from the healthcare professionals. You can ask to be referred to your local PR programme.



What are your tips for people with PF to get active?

I have a number of key sayings that anyone who has done PR with me may well recognise!

- **‘Stop before you have to’** – pace yourself so you don’t need as long recovery time.
- **‘Breathlessness can be healthy not harmful’** – it’s a normal reaction to exercise.
- **‘Think elite athletes’** – when an athlete gets breathless after their exertion they employ the same strategies you do to get their breath back. Use recovery positions and allow yourself to be breathless until the first signs of recovery and then work on slower deeper breaths.
- **Something is better than nothing** depending on your ability and fibrosis you may be able to do resistance training with weights or you may find you benefit from spending more time standing. This will help to engage your core muscles and improve your posture.



What simple and safe exercises can people with PF do at home to keep active?

It all depends on what people can do. It could be spending more time in a standing position to walking a bit further. Standing on one leg is a good means of strengthening the leg you're standing on and challenging your balance, start off by holding on to something. Chair based exercises can also help, from leg kicks, heel and toe raises, to sit to stands using and then not using your hands.

Do you have any breathing/ calming techniques for people with PF?

If you're feeling very breathless or panicky often the feeling of air moving across the front of your face can help. Let yourself breathe at the speed you need but then try to slow down and deepen out. Some people find breathing in through the nose but out through the mouth helpful as in sniffing a rose and blowing a candle out. Don't be over concerned about what part of your chest is moving.

Do you have any advice on how people can keep mentally fit this winter?

- **Stay connected** – meet up with family and friends when you can. Use facetime calls if necessary.
- **Think about what you eat** – there's so much research to show that eating well can improve your wellbeing and your mood. The food we eat can influence the development, management and prevention of numerous mental health conditions including depression and dementia.
- **Stay hydrated** – even though its winter remember to keep hydrated, it's good for your lungs.
- **Learn something new** – challenge yourself to learn a new skill to keep your brain ticking over.
- **Reach out for support** – if you feel concerned about your physical or mental health reach out for support though your healthcare professional or GP. And of course, APF is a great resource and support for anyone affected by PF.

“I'm certain that people who feel physically optimised will have more mental resilience to cope with living life with a long-term condition.”

Lorna Brown

To find out more head to APF's exercise information page on their website:
www.actionpf.org/information-support/exercise

Life with PF

What we've learned



Living with pulmonary fibrosis is different for everyone. How patients and carers make the most of every day in a changing landscape can really help others. Here they share some of their insights and experiences.



“Talk to family and friends about it and keep talking – some will take a while to understand what it actually means for your life (even after 14 years some of mine still don’t comprehend and ask if I’m better!!!).”

Angela Beardall



“I will echo some of the others here – don’t expect people to realise how ill you are, do pulmonary rehab early on, try chair yoga and meditation and look into palliative care as soon as possible. Finally, focus on enjoying each day as much as possible.”

Wendy Dirks



“Ask lots of questions. There are no dumb ones. Look for information far and wide. Share your feelings with your nearest and dearest and listen to them – they’re also finding it hard. Most of all, stay as positive and as fit as possible.”

Richard Flanagan

My Life with PF: Elaine

Elaine was diagnosed with IPF in her 50's. At the time, she was living a full and active life teaching dance exercise.

Elaine is a Keep Fit Association seated exercise instructor and runs sessions to demonstrate simple moves you can do at home to keep active.

Seven years on from her diagnosis Elaine talks to Insider about what keeps her physically and mentally active.

“Life with PF can be a bit of rollercoaster. I've had ups and downs along with a tough period of depression which sparked me to have major re-think to shift my mindset. I began by setting simple goals and stopped comparing my current situation to the things I could do in the past. I know every day is different with PF. If I have a bad day, I just acknowledge it and do as much as I can. Knowing when to rest is so important.”

Helping others has been a game-changer for me.

I run a voluntary theatre company with my daughter for adults with various disabilities. There's a little bit of dancing and a lot of laughing. I was humbled to be nominated as a community champion for my work. The real reward was the improvement in the groups mental and physical health which in turn had a hugely positive impact on my wellbeing and health. I've recently set up a support group for others with pulmonary fibrosis in Bridgnorth and Wyre Forest.

My advice to anyone with PF is to keep as physically and mentally active as you can. Even if it's just one small thing you do each day to keep active. I'm motivated by my ambitions and plans for the future and currently writing a book which will include life with PF. Watch this space!”



“Reaching out to APF has helped me enormously. I now do everything I can to support others and raise awareness.”

Elaine Kirby

Seated exercise – for an easy start!

- Put on some music you love, choose a steady beat and something you can sing along with also helps. Singing will help your breathing but keep it soft and gentle.
- Make sure you are sitting in a firm and stable chair with a good support for your back.
- Sit upright, imagine a balloon on a string holding your head up, this will help keep your spine aligned and lift the diaphragm which will help you with breathing and improve your posture. Sit with knees hip width apart and feet on the ground.
- Once you have the right seated position and music is playing, start by tapping your feet to the music, tapping hands on knees, clapping along and warming up your body. Move on to some gentle marching steps then side to side steps and reaching out with your arms to the sides and in front and build up to raising hands as far as you can, try not to keep your arms up over your head for more than a count of 4.
- Start with one song and move on till you can do 2 or 3.
- Always go back to how you started, return to gentle breathing and there you are, a start to building up an exercise plan that suits you.
- Always work to your ability and there is no prize for overdoing it.
- Another good tip when the day demands you take it easy is to do some very simple stretches during the TV adverts. Tap your feet, move your legs back and forth, but add a little movement into your day to make a difference to how you feel.
- Find a local Keep Fit Association Instructor who offers Sit and Stay Fit classes for a fun way to do more.

60 seconds with...

Oxygen Nurse Sara Mason

“Needing oxygen is not the end, but the beginning of reclaiming your life and getting back to doing things that were becoming difficult. Having oxygen can have a tremendously positive impact on your quality of life.”

Sara Mason

Sara Mason manages the NHS home oxygen service for North Cumbria. She's responsible for around 600 patients who have oxygen at home. Sara also recently set up the North Cumbria Pulmonary fibrosis support group which keeps her on her toes!

Why do patients need oxygen?

Contrary to popular belief oxygen is not given to relieve breathlessness. Patients primarily need oxygen to rectify Hypoxia, a lack of oxygen in the blood. Patients can be breathless due to their lung condition but have normal oxygen levels and vice versa. The primary intended outcome of oxygen is to improve quality of life or prevent cardiac problems.

Can you tell me a bit about the practicalities of using oxygen?

There are different types of equipment and each patient is assessed individually to see which one suits both their lifestyle and their clinical needs.

Long term oxygen therapy (LTOT)

– LTOT is usually given via a static oxygen concentrator for a minimum of 15 hours a day. Most patients use their LTOT overnight.

Ambulatory oxygen therapy (AOT)

– Some patients' oxygen levels fall when they move about. Oxygen may help patients to be more active, which in turn benefits lung condition. For AOT patients either have to carry or wheel a trolley with them and this may be not possible for everyone.

Some patients will use a combination of LTOT and AOT and may need different prescriptions for both. Most people choose nasal cannula as they are more inconspicuous and don't have to be removed to eat and drink.

What are the health and safety issues that patients need to be aware of with oxygen?

Safety always takes priority when it comes to us prescribing oxygen. All oxygen prescribers must legally complete a risk assessment. We consider things like where people live, clutter, smoking, mobility, and memory issues. We do risk assessments each time we see a patient and do regular home safety visits.

There are also practical tips and advice, do's and don'ts, such as not using oil based products as this can cause burns to the skin. Patients need to be careful around heat sources, not just fires but things like hair straighteners.

What's the impact of the cost of living on oxygen?

If your oxygen equipment is dependent on electricity, you'll get the money used to power the machine refunded back to you. You must send your bank details to your oxygen supplier. If you're having any financial difficulties you should speak to your oxygen nurse or the provider as there may be alternative equipment or it may be possible to be moved to monthly payments.



What changes have you seen in patients as a result of using oxygen?

Amazing changes! Patients describe getting their lives back. I have seen people who could only walk a few metres for a few seconds be able to get out of their house for a walk, meet family and friends and resume hobbies. People have commented how they often sleep better and feel so much more alert and bright. When oxygen is prescribed appropriately it can be a game changer in terms of helping patients deal with their respiratory condition.

What inspires you about the patients you work with?

I've got patients who strap on their oxygen and go up the fells, go dancing, work on their farms and I've another who swims with her cylinder at the side of the pool. I love seeing how people get on with their lives and are able to do the things they love again.



The support group set up by Sara

For further information about oxygen and how to be assessed please visit:
www.actionpf.org/information-support/oxygen

Research round-up

Over the past two years you've helped us to identify the top ten research priorities for progressive pulmonary fibrosis. We couldn't have done this without your support alongside the James Lind Alliance. Patients, carers and clinicians have been at the forefront of setting the future priorities for generations of researchers in the UK and across the world. Here's the top ten.



- 1 How can the **diagnosis** of PPF (progressive pulmonary fibrosis) be improved in terms of **accuracy and the time taken** (screening programme, early signs and symptoms that could be detected in primary care, blood markers, imaging, biopsy, artificial intelligence, etc.)?
- 2 Can **new treatments** other than pirfenidone and nintedanib **slow, halt or reverse** the progression of PPF?
- 3 What can be done to improve the speed and accuracy of PPF **diagnosis in primary care** (e.g. training, integration of case-based studies in GP training, awareness campaigns)?
- 4 What is the **best time** for drug and non-drug interventions (pulmonary rehab, oxygen therapy, psychological support) to start to **preserve quality and length of life** for patients with PPF?
- 5 What are the best ways (drug, non-drug and aids) to **treat cough in PPF**?
- 6 Would **early treatment** delay progression, lung function decline, and improve survival in PPF?
- 7 Which therapies will **improve survival in PPF**?
- 8 What treatments (drug, non-drug and aids) can **reduce breathlessness and phlegm production** in PPF?
- 9 To what extent do different interventions (pulmonary rehab, oxygen therapy, psychological support) impact **length of life** in patients with PPF?
- 10 Can **new treatments** for PPF be **developed with reduced side effects**? Does how the drug is delivered (e.g. oral, nebulised, through a vein) affect potential side effects of the drug in PPF?

Deciding upon the final Top 10 research priorities was incredibly challenging. Questions not included in the Top 10 remain very important to be answered. All the identified unanswered questions will be available for researchers to see on the JLA website and the complete findings of the process will be shared widely.



What happens next?

APF is taking action by investing over half a million in PF research. Over the next few years we will review our progress and ask ourselves – which questions are now being answered in research as a result of this work? Where are there still gaps? We will ensure there is a strategy for investing time and funding across the research priorities with a focus on collaboration and innovation.

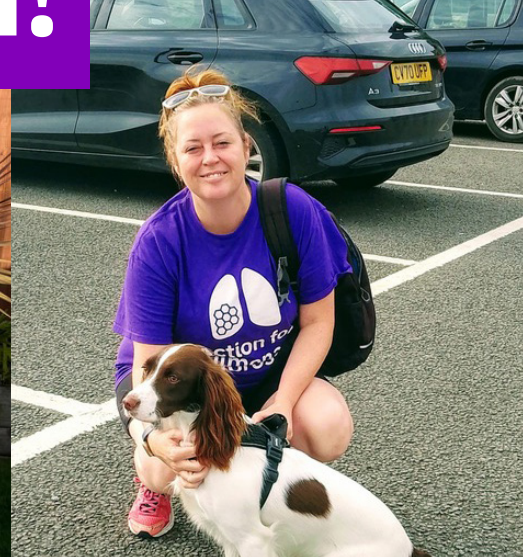
Ruby Rai, whose mother died of pulmonary fibrosis, says:

“This really feels like a landmark moment for pulmonary fibrosis. Being involved in the process was an empowering and emotional experience. It's too late for my mother but I hope this takes us one step closer to finding better treatments and ultimately a cure for this horrible disease.”

Fundraising



Thank you!



Throughout Pulmonary Fibrosis Month this September, our community joined forces to raise vital funds and awareness. Supporters up and down the country got involved by; Going the Distance, Creating a Stir and turning workplaces Purple for PF!

Every penny raised during PF Month will help us continue our vital work. From our team of dedicated telephone befrienders, our campaigning work to create a better future for everyone affected by PF, to ground-breaking new research – your fundraising will help us change lives.

Remembering our loved ones together

If there's someone you will be remembering this Christmas, we'd love for you to join us in December (keep an eye on our Facebook page for details) as we come together to remember loved ones we have sadly lost. Our remembrance event will take place on APF's Facebook page.

We can light candles together, remembering happy moments at this special time of year. You will be very welcome to use the live chat to share the name of the person you are remembering, and any poignant memories you would like to share with our supportive community.

If you'd like any further information please call **01733 475642** or email **sharon@actionpf.org**



For the second year running, **Nowell Meller Solicitors** changed the colour of their logo to stand in solidarity with all those affected by this devastating disease. Colleagues raised funds by holding their annual dress down day in aid of APF.



We would like to thank **Trevi Therapeutics** for once again sponsoring Pulmonary Fibrosis Awareness Month.



Holmes Millar kicked off their charity of the year partnership with APF by changing the colour of their logo and starting their fundraising challenge to collectively as an office, cover a distance of 30,000 - 50,000 km in memory of their much-loved colleague Carol Rafferty.

Our support line

9 out of 10 people say the APF support line has made them feel empowered. Below are some of the comments we've received...

"This call has put my mind at ease."

"This call has cheered me up and given me hope."

"You have a kind voice, given me my positivity back as well as questions to ask the medical team."

"The whole team should have a badge – The Golden Team – you are all amazing."

Pauline works on APF's support line. She qualified as a nurse in 1986 and since then she's worked in both respiratory and endoscopy medicine.

"The calls really do vary week to week. The top issues tend to be around diagnosis, medication and symptom management. Other questions range from dealing with a new diagnosis to benefits information. I've noticed an increase in calls from people who are not sure where to turn next. By talking it through on the support line they end the call with a clearer pathway and knowing what to do next.

Being able to talk openly and confidentially to someone who understands pulmonary fibrosis can be a lifeline. I feel so privileged that people feel able to share their concerns with me at such a worrying time. I learn from every single caller."



**Are you a good listener?
Do you enjoy supporting others?**

If so, we'd love to know if you have a few hours a week to help provide support over the phone?

APF has an amazing group of volunteer befrienders who support people living with PF with befriending phone calls. The befriending service is invaluable for people who are feeling isolated and in need of emotional support. In turn volunteers tell us the hugely positive impact it has on them knowing they're helping others. APF offers training and guidance for all volunteers.

If you'd like to find out more, please do call us on **01733 475642** or email **support@actionpulmonaryfibrosis.org**

The support line is open to anyone affected by pulmonary fibrosis – whether you're a patient, carer, relative, friend or healthcare professional. All calls are taken in confidence by the support services team.

 Support line
01223 785725

 support@actionpf.org

Dates for your diary



BBC Lifeline Appeal

APF is absolutely delighted to be chosen as the subject of a national TV awareness and fundraising appeal for the BBC. The BBC Lifeline Appeal for APF will be on BBC 1 and repeated on BBC 2 in mid December. Filming is taking place during November. This is an amazing opportunity to put the spotlight on pulmonary fibrosis at a national level and raise much needed funds to support our services and research. More details with exact date to follow!



23 November 2022

‘Spotlight on PF in Scotland’ – APF hosts a virtual event to talk about their work in Scotland

www.actionpf.org/news/spotlight-on-pulmonary-fibrosis-in-scotland



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