Feature story

New APF website goes live!

We asked you what would make the biggest difference to your daily lives. You told us that specialist, up-to-date and accessible information was a top priority. Our new website is just what you asked for. It has over 70 pages of information, advice, personal stories and details of all support groups across the UK.

We’ve also included a Coronavirus Hub, where you can find all you need to know about the virus and ways to support yourself and loved ones whilst in self isolation. The hub is constantly updated as information, advice and knowledge changes.

Becca Thomas, APF Digital Communications Specialist, said: ‘We will be working hard to keep improving the content and design of the website so that everyone can feel empowered with the right information. Please take a look at www.actionpf.org and tell us what you think. And let us know if we’ve missed anything!’ If you have feedback do get in touch at info@actionpf.org

‘Fresh and dynamic. Better than we ever expected.’

‘All I can say is, wow!’
Personal stories

Still standing – after four months of shielding!

Action for Pulmonary Fibrosis Chair Steve Jones lived with IPF for eight years before having a single lung transplant four years ago.

It is now nearly four months since my wife and I started shielding. On balance, it’s not been too bad. We are lucky to have a garden and live in a village where we can go out for walks, while easily keeping two metres away from others. The early anxieties about whether pulmonary fibrosis patients were ‘on the list’ or not and the confusion about letters seem a long time ago.

In some ways, we have enjoyed shielding. Spending more time at home and travelling less on APF business has been good. I am also proud of the way APF quickly scaled up our support line to help those who have been finding shielding difficult and persuaded the government to recognise ILD patients as ‘clinically extremely vulnerable’.

The main downside for us has been not seeing our grandchildren, though we can now meet them in the garden. Also, I don’t know about you but, after months of lock-down, I miss doing the simple things like seeing friends, buying our own groceries and watching life go by while sitting in a café!

From 1st August, the government advice is to adopt ‘strict social distancing rather than shielding’. We will be able to go outside to buy food, visit places of worship and return to work so long as we can observe strict social distancing.

After shielding for so long, it will be difficult to decide how much to relax. The government will issue further advice but APF will also be there to help you assess the risks associated with different activities and to decide what you, as an individual, feel safe doing. And, to end on a positive note, we’ve got this far and I believe have all shown that we are more resilient than we think!

Support

PF Awareness Month – The time to talk about lung fibrosis is NOW

Action for Pulmonary Fibrosis is joining people across the world during PF Awareness Month in September to spread the word about the disease.

We know that many of you like to contribute and feel part of the worldwide PF community during this special month. And there is no-one better than you – the patients and families who know exactly what it means to live with this disease – to raise awareness.

APF is gearing up to Pulmonary Fibrosis Awareness Month, and IPF World Week which falls in the middle of the month on 12-19 September.

As we face the new normal, with Coronavirus still very much in the community, we are still hearing the feelings of isolation and ‘forgotten about’ that you have been experiencing. We know that there has never been a tougher time to live with a lung condition. People with pulmonary fibrosis perhaps understand better than most what Covid-19 might feel like.

To support you during PF Month we will be hosting a research webinar and holding a series of podcasts around mental health.
Create a Stir! in PF Awareness Month

This September, during Global Pulmonary Fibrosis Awareness Month, we are asking all our wonderful APF supporters to get involved and Create a Stir! for people affected by PF. Invite your friends and family to join you to help us raise awareness and funds, and you will make a big difference to the 70,000 people affected by PF in the UK each year.

Getting involved is easy – we are asking you to hold a party and we will give you all the support you need. There are three types of parties you can host. Just decide what type of stir you want to create and ask your friends to make a donation to join your party!

Let's Brew This!
Simple and traditional, everyone loves a brew to catch up, have a natter, eat treats and raise some dough.

Shaken or Stirred?
A cocktail party is a great opportunity to gather together good friends and enjoy a delicious cocktail. You can swap recipes and get creative with some home-made decorations.

Milk it!
A milkshake party is a great way to for children to fundraise and get their friends involved. It could be a double chocolate milkshake or even a fruit and yogurt shake. Inspire your little ones to try out their own recipes and get imaginative!

We'll provide you with everything you need to make your party a success. Banners, balloons, invitations, recipe cards and much more. Sign up today on our website www.actionpf.org to Create a Stir for those living with pulmonary fibrosis.

Every penny raised will help us in our fight to:
- raise awareness of pulmonary fibrosis and its impact on patients and families
- increase support for those affected by pulmonary fibrosis
- grow research into the disease and treatments, which could one day lead to a cure.

If you are shielding, you can still host your own Create a Stir at home event by grabbing your phone, iPad or laptop, and having your party via video link. Just invite your loved ones to join you and make a donation. We can help you to navigate Zoom, WhatsApp group calls and other free online ways of connecting with your friends and family.

If you’d prefer to do it in person, we can help you make sure you follow the government guidelines of social distancing to keep you and your party guests safe. Mae and Louise Saunders (pictured) will be hosting a milkshake party this September and raising money for APF.

Mae said:
‘We are really excited to host our own milkshake party and invite some of our friends to try out our own recipes. We will be asking everyone to donate £3 each for a milkshake and a homemade cookie. We hope to raise lots of money that will help people with pulmonary fibrosis.’

Don’t forget, if you are planning a personal challenge to raise funds for APF, email the team and let us know what you are planning at fundraising@actionpf.org.

Friends and colleagues of Mick Johnson, who starred in the BBC1 series Ambulance, are collectively walking 75 miles in his memory. Sadly, Mick died in March, having been diagnosed with PF in 2018. Close friends at Tollgate Ambulance Station in Stafford worked within distancing guidelines to hold their fundraising event on what would have been Mick’s 75th Birthday in June.

Lesley Cully lost her mum to PF in 2017 and last year raised over £3,000 running the London Marathon in her memory. Lesley then joined the 2020 London Landmarks half marathon but, when the run was postponed, she went ahead with her own Local Landmarks challenge. ‘I’m delighted to support APF. It’s a fabulous charity and every penny goes to such a great cause,’ Lesley has also been busy making face masks using left over fabric. So far she’s made masks for over 40 people, raised over £400 and has sent them all over the country and to America!

‘This new virus is showing how terrible it can be to not be able to breathe and so to protect in a small way against that by wearing a mask and raising money at the same time was a perfect fit,’ she said.

Lily, aged only nine, wanted to raise funds for APF in memory of grandpa Keith Barnard. She designed a poster to promote her event – cycling 150 times up and down her driveway at home – and managed to raise £175. Thanks Lily for cleverly adapting your fundraising event during lockdown and staying safe!

APF Support Group News • Summer 2020

Fundraising stars

During September’s Awareness Month, we are asking for our supporters to do something amazing and donate their celebration to Pulmonary Fibrosis Month. Whether it’s a birthday, anniversary or retirement, you can ask friends and family to make a donation to APF in lieu of a present.

Facebook Fundraisers are quick and easy to set up. Facebook will prompt you to set up one for your birthday or you can do this yourself. You’ll be able to also be able to add a donate button to your page, posts and video, making it easy for your family and friends to contribute in a few taps. Whatever time of year you’re celebrating your special occasion Facebook Fundraisers are an easy way to raise money for APF.
**Stories from the NHS frontline**

**Action for Pulmonary Fibrosis Chair Steve Jones shares his thoughts on the NHS frontline workers, and we hear first-hand from two clinical colleagues.**

Covid-19 brought changes for all of us,’ says Sandra Olive, Nurse Consultant at Norfolk and Norwich University Hospital. “Wards and clinical teams reorganised, guidance for practice was re-written and skills refreshed in preparation for our altered roles. I spent the first few weeks providing training in respiratory nursing and hands on support for the inpatient nursing teams – an education for me too, having not worked for long periods on wards previously.”

Mark Major, Specialist Nurse with Hull University Teaching Hospitals also reflects on the challenge. “We were planning for, and expecting the worst. Clinics closed, wards emptied, new makeshift ICUs opened and staff redeployed into the unknown.

‘I returned from holiday early to help steady our pulmonary fibrosis ship. All clinics were converted from face-to-face appointments to telephone consultations and home visits were urgent care only. We manned our phones and reassured patients as the calls came in. I provided teaching on Covid-19 wards to staff unfamiliar with high flow oxygen in readiness for the influx of patients. Fortunately the wave never came – more of a ripple! Demand for beds was steady but low.

We found our new way of reviewing patients strange but more efficient and some of our patients preferred it.”

‘We are now planning our recovery phase and reopening clinics, albeit in a new look system without relatives and loved ones. We remain in unchartered waters but we are seeing light at the end of a very dark tunnel.’
Making Carers Visible

At Action for Pulmonary Fibrosis we know that a diagnosis of pulmonary fibrosis has a huge impact on everyone in the family. While the patient is always at the centre of our work, we also want to support carers and families. During Carers’ Week in June we held an online Carers’ Forum to gather the experiences and views of those of you in the ‘front line’. It was a privilege and a revelation to hear from those who took part.

Here are some of the highlights:

• Although most people agreed that the term ‘carer’ isn’t perfect nobody objected to being called a carer. ‘Whilst you are a husband, wife or partner personally, for people looking in you are a carer.’ The American term ‘care-giver’ got a resounding thumbs down!
• Information and signposting to charities like APF at the point of diagnosis was badly lacking.
• Knowledge of doctors and nurses not involved in respiratory care was generally poor. ‘I have been in a hospital emergency department when a doctor ‘Googled’ pulmonary fibrosis,’ said one carer.
• Agreement that palliative care – although a term many patients are frightened of – should be supported carers’ group she set up last year. Dee cares for husband, Roger, who was diagnosed with IPF in July, 2016 and the couple also set up the West Kent PF Support Group. With my background as a Complementary Therapist in cancer and palliative care and my needs as a carer myself, I felt it was a natural progression to start a carers’ group last year. It provides an open, confidential, safe space for carers to express their worries, concerns and fears along with being able to laugh and cry without upsetting loved ones. With the lack of psychological support for patients and carers from the point of diagnosis, support groups have been invaluable. As a carer myself, I knew that others must share my worries and fears. There isn’t any particular format, we just talk about things very naturally and encourage people to express their emotions.’

‘As a carer myself, I knew that others must share my worries and fears.’

Supporting carers in West Kent

We asked Dee Bryan to tell us about the carers group she set up last year. Dee cares for husband, Roger, who was diagnosed with IPF in July, 2016 and the couple also set up the West Kent PF Support Group.

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‘As a carer myself, I knew that others must share my worries and fears.’

Support and connection

Details on how to stay connected with friends and family via WhatsApp, Zoom or Skype

Your wellbeing

Support and advice on maintaining good mental health during the crisis

Videos

Lots of great advice on exercise, diet, zooming and much more.

The Hub is constantly updated as advice and guidance changes.

If you think we’ve missed something or have unanswered questions please let us know by emailing us at info@actionpf.org or call our Support line on 01233 785 725.

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And who better to tell us how this group helps than three of the members themselves?

‘The group has been a great support to me. Before my husband’s death there was good advice from the others which helped me get information and support. Since then it has meant the world to me to speak to people who know they will face a similar end and be alone. They are there for me anytime I need them.’

‘I feel like our little group are all on a journey through pulmonary fibrosis together and when the road gets rough for one of us, the others are there to help, support and comfort. It helps me to know that as heart-breaking as it is when you reach the end of the road, with family and friends around you, you will get through it.’

If you would like to talk to Dee about setting up a Carers’ Group please contact her at deebryan@me.com or call on 07775 616769.

And you’ll find support and advice on our website actionpf.org/information-and-support/carer-family-friends

Wendy Dickinson, APF Trustee

‘Just knowing the others were going through similar problems has really helped as it’s reassuring to know I am not alone. Also, to have a little rant or let off steam in the company of others that aren’t going to judge you, but listen with empathy, especially as the disease progresses.’

Support APF Coronavirus Hub – all you need to know in one place

The Covid-19 pandemic has been with us for six months and the information coming from all sides can, at times, seem overwhelming. To support all those living with pulmonary fibrosis we have set up a Coronavirus Hub on our website to bring together, in one place, all you need to know to stay safe.

Check it out here actionpf.org/information-and-support/coronavirus

FAQs

All your questions answered, from advice on wearing facemasks to changes to guidelines on shielding

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Health tips

Techniques to help with breathlessness

Breathlessness can be a frightening and distressing symptom of pulmonary fibrosis. You can learn how to minimise, cope with and manage this symptom – and make a big difference to your quality of life.

Pursed-lips breathing
Breathe in through your nose, then purse your lips as though you’re going to blow out a candle. Blow out only for as long as is comfortable – don’t force your lungs to empty any more than feels natural.

Blow-as-you-go
Blow-as-you-go helps make tasks and activities easier – especially those that make you breathless. You can use it with pursed-lips breathing. For example, when standing up, breathe in before you stand up, and then blow out as you stand up. Try using pursed lips as you blow out.

Paced breathing
Paced breathing is useful when you are walking or climbing stairs. You pace your steps to your breathing. You can use it at the same time as pursed-lips breathing and blow-as-you-go. Breathe in for one step and then take either one or two steps as you breathe out. Take more steps as you breathe in or as you breathe out, if that feels better for you. Try different combinations to find what works best.

Start singing!
Some patients have found singing to be beneficial, although it doesn’t suit everyone. A number of support groups have invited singing coaches to their sessions and found this very useful.

Feeling out of control
For those times when you are too breathless or anxious to manage breathing control, simply:
- Gently fan yourself
- Lean forward
- Focus on longer out-breaths.

Volunteer telephone ambassadors waiting for your calls

A new APF telephone service is now ‘live’ to support people living with pulmonary fibrosis during the Covid-19 crisis. Action for Pulmonary Fibrosis has trained telephone support ambassadors to add to our existing ILD nurse-led Support Line service. Our volunteers are either PF patients, carers or former carers and they understand just how tough life with pulmonary fibrosis can be.

You can refer yourself or we can receive referrals from health professionals and support groups (with your permission), for anyone over 18. Anyone who would appreciate a call should let us know at support@apf.org or on 01223 785725.

We’d be happy to answer any questions you have, check that you are getting the support you need and to signpost you to other services, including PF support groups and our own nurse-led Support Line.

The volunteers are given training (including on wellbeing and safeguarding) and have a support supervisor. They also have a What’sApp group. Volunteer Administrator Emma keeps everything on track with details of who to call.

Nurse consultant Dr Karen Marshall said, ‘I have been very interested in the psychological impact of respiratory conditions and I was delighted to be asked to work with APF to help train volunteers, developing their current skills to discuss emotional wellbeing with people they may be in contact with. It is important to address physical and psychological needs and I was so impressed by the enthusiasm of the volunteers. I know they will make such a huge difference to many people. APF will be running more training soon and we’d love to hear from anyone who is interested in becoming a telephone support volunteer!’

Gordon Harrison, Vice Chair of Sheffield PF Support Group said, ‘As support group leaders, our first priority was to get members recognised by the Government as being extremely vulnerable, which we did with the assistance of APF.

‘What is proving to be challenging now is how best to support those who are trying to cope emotionally with the twin pressures of a serious health condition and long-term self-isolation. That’s why we are so pleased to hear about the telephone support service for those who, in many cases, just need a sympathetic but informed ear’.

Sarah Lines, Exeter Support Group lead and Respiratory Nurse Specialist, commented, ‘With limited work time our conversations often focus on clinical needs. I welcome the work that APF is doing to provide telephone support volunteers for peer support and will be ensuring that our patients are aware of this valuable help.’

Karen (second right) at the British Journal of Nursing Awards last year

Sarah Lines (next to display stand on left) with colleagues pre-Coronavirus.

Patient reaction:
‘We talked about dogs, the weather, disabled horse riding, Cumbria… just lovely...’

‘I welcome the work that APF is doing to provide telephone support volunteers for peer support and will be ensuring that our patients are aware of this valuable help.’

Sarah Lines, Respiratory Nurse Specialist

You can find more about breathlessness on our website: actionpf.org/information-support/breathing-techniques

Hull York medical school also has a useful guide to living well with breathlessness: hylms.ac.uk/assets/docs/research/bringing-breathlessness-into-view.pdf

and carers may want to look at this supporting breathlessness resource: supporting-breathlessness.org.uk

Gordon enjoys a pint, pre-lockdown!
Support Group Round-Up

**Zooming through the Coronavirus crisis**

You’ve probably noticed that our regular round-up of support group activities looks slightly different this issue! We love to feature your events, talks and meetings but the Covid-19 pandemic has put paid to most things ‘normal’. However, you haven’t let it stop you connecting with us and with your support group friends. We’ve been really impressed by the efforts of many groups to keep in touch. We can’t mention every group here (you know who you are!) but here is a shout out to a few, and news of what APF has been doing to stay connected.

When lockdown was announced on March 23, few of us imagined how long and how difficult it would be. Even now the PF community still has the prospect of months more of restrictions to our normal lives until a vaccine or effective treatments are found. As well as the worry of having pulmonary fibrosis and the chance of being exposed to Coronavirus, we have also been coming to terms with not seeing friends, children and grandchildren for many months.

But – in the face of adversity we suddenly discovered an amazing new resource to help us cope: Zoom and online wizardry. What a blessing Zoom and other technology has been, not only enabling us to see and speak to our loved ones but interact as a group as well.

Obviously, nothing can replace face-to-face contact with other people but positives and possibilities have emerged from our experience of Zooming. For a start, many of us who remember pre-internet days, have learned new skills and new ways to connect which could really enrich our lives in the future.

Zoom has also been a brilliant way for APF to stay in touch with the network of 70+ support groups across the UK and for support groups to stay in touch with their members.

**APF’s first Zoom meeting**

Our support team, led by Debra Chand, organised APF’s first Zoom meeting just a few days after lockdown and over 30 group leaders took part to contribute to our support plans during the crisis and to tell us about how they were coping.

Support Group Round-Up (cont.)

It is a great mutual support network and we now hold Zoom meetings for group leaders every three weeks, alternating between national and regional meetings. It supports the leaders during a very difficult time and a bonus has been that our two new regional co-ordinators, Jo Ruck (Northern Region) and Gillian Trippner (Southern Region) are able to put faces to names as they both started their jobs after lockdown. They are looking forward to meeting you face-to-face eventually.

Support Group zoomers

Bolton PF Support Group has been leading the way with online meetings even before lockdown was imposed. Group leader, Steve Milward (pictured), says: ‘We realised that this was approaching and we arranged our first virtual meeting a couple of weeks before March 23.’

Steve did his research and decided against Zoom, instead choosing the free service, Google Meet as the platform for Bolton’s meetings. He has also organised weekly live pulmonary rehab exercise classes for members with the help of Tom Allerton, Specialist Respiratory Physiotherapist Principle Service Lead at The Royal Bolton Hospital. Steve says:

‘I’ve been on two eight-week PR courses and they were great. You are supposed to carry on the exercises at home afterwards but, despite all good intentions, not many people do. Bolton Age UK has kindly given us the services of physio Niall Bradley, Strength and Balance Team Leader, for our weekly online sessions. Everyone who takes part really enjoys it and feels the benefit. It’s not only good for health but is also a social and fun activity. Laughter helps to expand the lungs!’

Steve is even now planning for the future: ‘There are people who want to come to our face-to-face meetings – in normal times – but just aren’t up to it and some regulars who are just too poorly on the day. I already have a state-of-the-art webcam and we’ve received a local community grant to buy some new software and a video camera controller which will help us broadcast our meetings live into members’ homes. We definitely want to continue with virtual meetings post-Covid.’

Other groups that are embracing technology to support their members include St Georges (London), Tameside, Papworth, West Kent, Kettering, Derby, Nottingham, Leicestershire, Leeds, Sheffield, Manchester, Bolton, Reigate, Chorley and Preston, Imperial (London), Sutton Coldfield, West Bromwich and Berkhamsted. Please let our support team know if you have been Zooming.

**APF Support Group News • Summer 2020**

Wendy Dickinson, APF Trustee

And don’t forget WhatsApp

If you don’t fancy appearing on-screen or just can’t master the technology, WhatsApp on your phone or tablet is a great alternative. APF Trustee Howard Almond manages a WhatsApp group for the Plymouth and Exeter Support Groups with the help of ILD Nurse Specialist, Sarah Lines. There are around 20 members and many have never attended a face-to-face meeting as they are too far away or are newly-diagnosed. Howard says: ‘Early conversation was about getting supermarket deliveries and who to contact for support but now I post Covid-19 and research news and the work being done to get clinics up and running again. It works well and people can ask questions and raise issues whenever they like.’
Your feedback is invaluable – Thank you!

‘APF is run by people who have or know someone with PF. They know and fully understand the condition, how it affects the person, their lives and their families, friends and carers. They have everyone’s interest at heart and always go the extra mile to help, which means everything.’

A huge thank you to everyone who completed our Covid-19 Survey. We had an overwhelming response and have gathered feedback from over 500 people. You gave us some essential insights about how the crisis was affecting you. We also received some lovely comments which inspire us to continue to drive forward.

We received responses from every part of the UK

- 55% were from patients
- 30% were from family members and carers
- 53% of the family members and carers over half were partners and...
- 26% over a quarter a daughter or son

Isolated and forgotten

A quarter of you (25%) said you did not receive a letter advising you to shield at the start of lockdown and a third (31%) said this made you feel isolated and forgotten. Almost three quarters (73%) said the communication and information supplied by APF during the pandemic has been relevant. This is reassuring for us and we will continue to ensure our Coronavirus Hub is kept up to date.

Unsurprisingly the Covid-19 pandemic has made the vast majority of you more concerned about your lung condition and over half (54%) are concerned about not having regular tests at hospital.

APF has successfully campaigned directly with Health Secretary Matt Hancock on this to ensure that PF patients are given priority for lung function tests. We will be monitoring the situation to make sure the new system is working.

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As always, research and increased awareness of PF remain a high priority for our charity. As Pulmonary Fibrosis Awareness Month in September approaches we’ll be using the statistics, insight and anonymous quotes from you to drive awareness, understanding and fundraising for our work. The full report will also be available on our website.

Research focuses on Covid-19 impact

‘Just to thank APF for getting PF patients recognised as extremely vulnerable during the crisis. They had been forgotten which was really worrying and upsetting. Positivity is the key – knowledge and inspiration underpins this!’

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Research

Pulmonary fibrosis patients were initially not included on the list of extremely vulnerable people, which would give them access to priority support and services. APF campaigned to change this and PF was eventually included.

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Support

APF Telephone Support Line

It’s no surprise that the APF Support Line has experienced an increase in calls over the past three months. ILD Nurse Lucy is there to give tailored advice on pulmonary fibrosis. Recent enquiries have been about shielding and concerns over delayed appointments but lots of general questions about living with PF as well.

It is important for APF to keep in contact with our patients so that we understand your concerns and accurately represent and support you, so we encourage patients and carers to keep calling.

As one caller said, ‘If it’s not Covid the NHS doesn’t want to know. I feel abandoned. Thank you for listening and helping me form a plan.’

Find more information here: actionpf.org/information-and-support/support-line

Support line 01223 785725

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