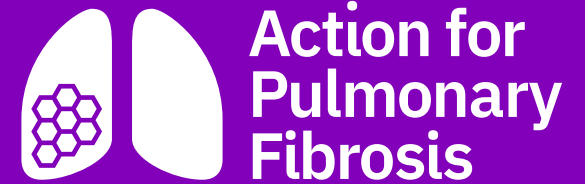


# I wish it was cancer



## Experience of Pulmonary Fibrosis in the UK



The largest post-COVID survey on the urgent needs facing people with lived experience of progressive fibrosing ILD.

**November 2023**

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# We demand change

Action

Summary  
About ILD  
Process  
Findings

Pulmonary fibrosis (PF) is an invisible killer. This report provides a powerful voice for the many people experiencing progressive fibrosing ILD (Interstitial Lung Disease).

It provides a platform for experiences that often go unheard and highlights the impact of PF on many aspects of daily life.

People with PF deserve to be heard and have equal opportunities to live a healthy and active life – these themes are clearly articulated throughout this report.

So often this is impeded due to the lack of recognition of the impact of PF. People who live with this condition often feel isolated and fearful.

The insight gathered in this report enables us to form recommendations for the sector that could create meaningful and enduring change.

It also lays the groundwork for future healthcare innovation, including the new national integrated care pathway from OneVoiceILD, and a timed pathway for care to ensure all patients get diagnosed and start care as quickly as possible, with a supportive network around them from day one.



**Louise  
Wright**

CEO, Action for  
Pulmonary Fibrosis

# Time is precious

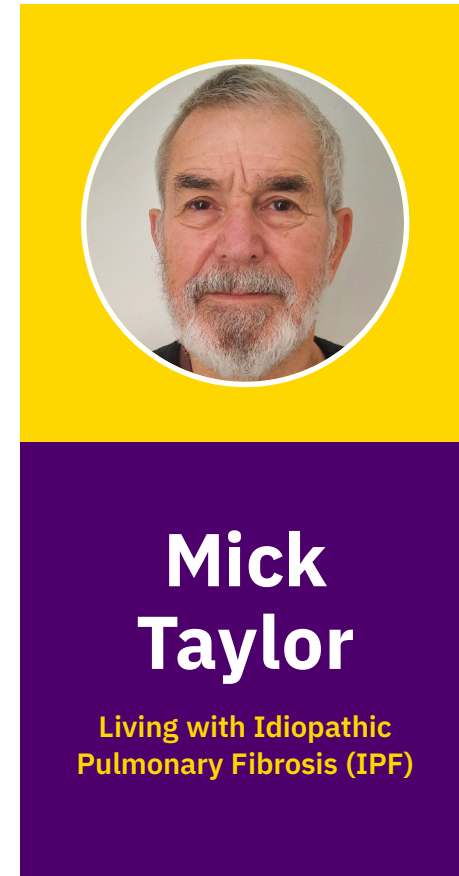
Living with lung disease is horrible. Breathlessness can feel like having a 25kg sack of sand tied around your chest. You cough a thousand times a day, you can't find your next word, you stumble out of exhaustion, you feel like a zombie.

What makes life more difficult as someone living with IPF is not being taken seriously. When you speak to anyone in the health service, being terminally ill should guarantee their time, patience, and empathy. The most important quality of your care is reliability and understanding what happens next including the next appointment. Uncertainty can negatively contribute to patient's mental health. It is clear in the report that more needs to be done here.

Multiple people in this report said they would prefer to have a cancer diagnosis. As someone who is also living with prostate cancer, I've seen how well cancer services can work, with support and care on offer, and better understanding in the public. This is a world away from PF.

Communication is paramount, and support needs to be made clearly available for everyone affected by PF. I didn't know about support groups or pulmonary rehabilitation until I'd spoken to Action for Pulmonary Fibrosis. Everyone should be referred directly to the charity at diagnosis so they can understand what is available.

This report is a vital step forward in demonstrating these issues, and will help improve services. Remember, time is precious. Quality of life is precious. Neither have been top of the agenda, and we demand change now.



# Executive summary

## About PF

Pulmonary fibrosis (a group of progressive interstitial lung diseases) is a fatal disease where the lungs become progressively stiffer and smaller. The only curative treatment is lung transplant, and current medicines can only slow progression.

## Who took part

Face-to-face or virtual workshops took place in every NHS region of England, as well as in Northern Ireland, Scotland and Wales.

**14** workshops were held across regions in the UK

**248** people participated in workshops and interviews

**1,025** people completed the anonymous survey



# Key themes

## Diagnosis



- Faster access to an accurate diagnosis to benefit from treatment as early as possible.
- Referrals to peer support and Action for Pulmonary Fibrosis at the point of diagnosis.
- Diagnosis shared more sensitively, delivered face-to-face with information about the condition, next steps, and the support provided within their integrated care system including mental health and wellbeing.
- Improved public and healthcare professional education alongside a timed pathway for PF diagnosis and treatment.

## Management



- There is enormous variation in care following diagnosis largely because not everyone recognises PF to be life-limiting.
- People want rapid follow-up and discussions about treatment and monitoring their condition. Everyone should have direct rapid access to the expertise and support of a specialist nurse with the option for remote contact.
- Care needs to be joined up with better communication and integration across services including ensuring GPs are equipped to support them.

## Access



- Improved referrals to sources of emotional support and information close to home.
- Vital services need improvement such as: condition-specific pulmonary rehabilitation, mental health support, dietary support, oxygen therapy and palliative care are frequently limited and involve extremely long waits.
- Joined-up care across regions is essential to improving services.

*“It’s an awful thing to say but **I wish it was cancer.** There would be more support if I had cancer.”*

Ovarian Cancer	IPF	
7,500	6,000	New cases (annually)
4,100	5,000	Deaths (annually)
43%	45%	5 year survival



# Why does PF matter?

Pulmonary fibrosis (lung scarring) describes the most aggressive group of progressive interstitial lung diseases (ILDs) where the lungs become progressively stiffer and smaller, eventually leading to low oxygen levels in the blood.

Life expectancy for people with PF is limited yet there is poor awareness of the condition. Survival at 5 years for Idiopathic Pulmonary Fibrosis (IPF) is worse than many cancers including ovarian cancer.

**70,000**

in the UK are  
living with PF



**1 in 100**

of all deaths are from IPF

**3-5 years**

life expectancy for IPF

**1 in 3**

people in the UK have  
never heard of PF

**46%**

of people with IPF  
survive 5 years

# Living with PF

People with PF can have difficulty breathing, a constant debilitating cough, struggle with a dry mouth and nose, and lose strength and energy, “like someone pulled the plug”.

Doing the simplest things, like walking around the house, are frequently overwhelmingly difficult for people with PF.

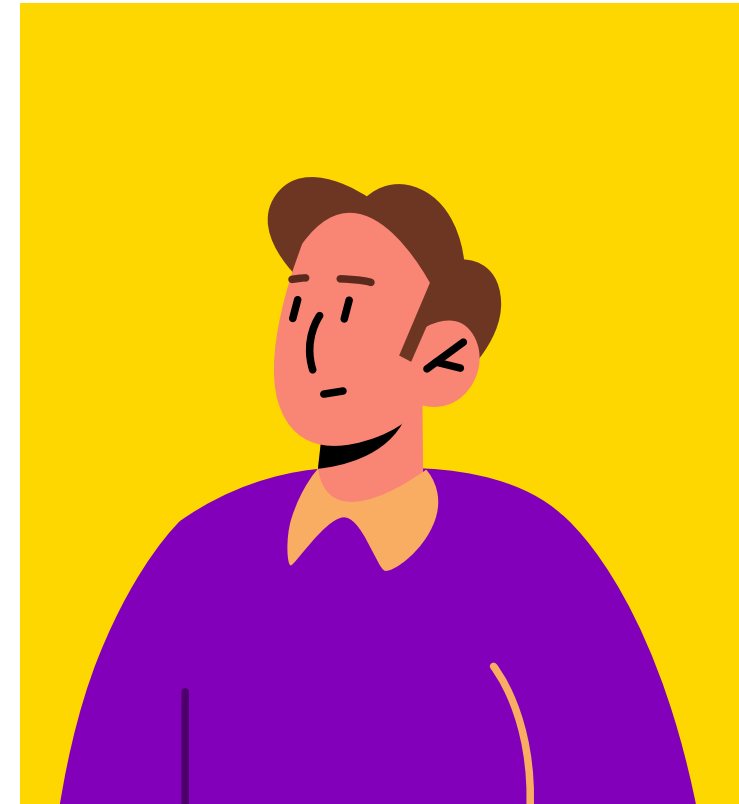
For people reliant on oxygen there is added stress and worry as supply is unreliable in parts of the country. People have constant anxiety about ordering oxygen and live in fear of running out with many feeling housebound.

“People can’t see this illness,” someone told us, “they say you look well but they don’t know how you feel inside”.

*“Everything takes a lot longer.”*

*“I am at a stage where even basic things are a challenge: washing and dressing, keeping a routine, going outside.”*

*“Consultants should consider the impact on overall quality of life. They never ask how you are coping.”*



# What is important to people with PF?

Through this survey and consultation, people with lived experience of the range of progressive ILDs shared their experiences and challenges they face. Each story is unique but together paints a distinct picture of the challenges affecting people with PF in the UK.

We sought as many different voices as possible from a wide range of backgrounds, particularly from groups more impacted by PF. However, we note the challenges doing so effectively and more needs to be done to meet the needs of diverse groups.

People cited a lack of recognition that PF is life limiting with many stating the diagnosis was worse than cancer. There is no denying the impact cancer has on a person's life, however the prognosis for IPF is worse than the average cancer, and support provided is often minimal in comparison.

This report examines how current services are being delivered and in presenting these insights creates a springboard for change.

These valuable insights create a starting point for influencing meaningful and long-lasting change which will have a significant positive impact on people's lives.

Over an eight-week public consultation period, a range of views and experience of health and care was collated from people affected by PF and wider stakeholders. They spoke about the variability that currently exists in specialist ILD services and what, for them, good care and support would look like.

## **This report aims to:**

- Identify common challenges affecting people with PF
- Amplify the voice of this under-represented group sharing their experiences
- Highlight common themes in the delivery of services to suggest improvements to existing information, services and pathways, guiding thinking around developing or identifying innovative healthcare solutions.



# How we engaged people with PF

Group workshops, individual interviews and an anonymous survey, available online or via the post, formed the basis of this piece of work. This allowed a choice of method based on individual needs and how participants felt comfortable sharing their thoughts, feelings and experiences on what can be a very sensitive topic.

Face-to-face or virtual workshops took place in June and July 2023 in every NHS region of England, as well as in Northern Ireland, Scotland and Wales. Each workshop ran for between 60 and 90 minutes. Participants shared their experiences of PF services which allowed them an opportunity to share the challenges they face living directly (or indirectly) with PF.

A wide range of people of all ages took part, including people living with PF as well as carers and family members (including recently bereaved carers). We prioritised diverse voices with a range of protected characteristics for the interviews, including a range of ethnic groups, sexualities, and disabilities.



14

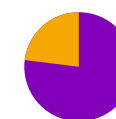
workshops were held across regions in the UK

248

people participated in workshops and interviews

1,025

people completed the anonymous survey



789 people with PF  
236 carers of people with PF

# What does it feel like to live with PF?

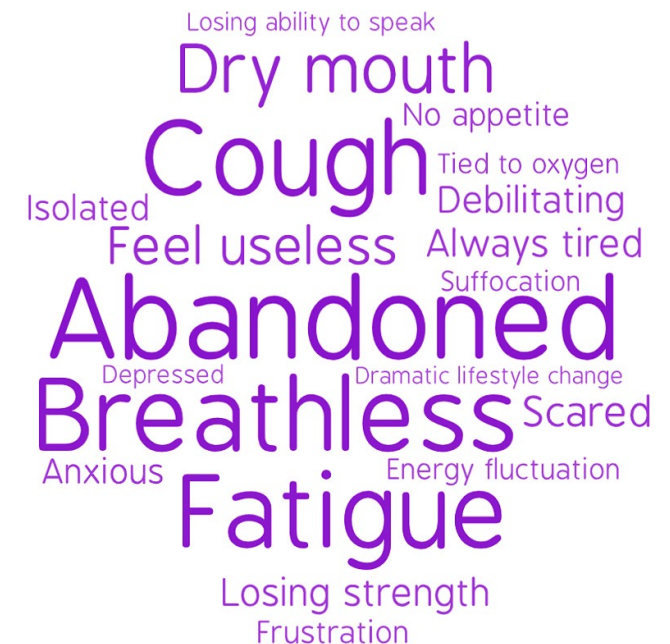
Many shared very positive experiences of excellent healthcare services and support. However, a powerful theme emerged that people with PF feel abandoned to cope with a serious and terminal illness, without the care and support we've come to expect from the NHS.

One of the most difficult challenges is coming to terms with the diagnosis – the short life expectancy, rapid progression and how much life changes. For people who were once fit and active, it is hard to accept severe and mounting limitations and give up on personal aspirations.

*"I feel totally frustrated at the rapid deterioration in my condition. I've gone from playing golf three times a week to barely being able to breathe in six months."*

*"What if you have no one to fight for you? You are in trouble."*

*"I'm trying to make the most of every day whilst knowing I'm terminal."*



# What is the hardest thing to cope with?

Despite being as serious and deadly as cancer, healthcare professional awareness and support for people with PF is much more limited.

PF support is often grouped with other, less severe conditions like chronic obstructive pulmonary disease (COPD) and asthma, despite having very different needs. Without adequate support, people face the profound uncertainty of how their PF will develop.

Family and friends can also lack awareness and understanding about how serious lung conditions can be. Several people commented that “no one believes you are dying” making living with the condition difficult.

It was clear that the most upsetting thing for everybody contributing to this report was the staggering level of mental health distress people are enduring without adequate support.

“People can’t see this illness,” someone told us, ‘they say you look well but they don’t know how you feel inside”.

**To everybody affected by PF who contributed, if this report can achieve one thing we want people to know how you feel. You deserve better.**

*“I put a brave face on all the time but inside I am falling apart.”*

*“PF is the ‘poor relation’ of terminal conditions.”*



# What needs to change?

People with PF told us they feel abandoned in three key areas: at their diagnosis, managing their condition and accessing the support they need for a better quality of life.

## Diagnosis

- > Fast and accurate diagnosis
- > Deliver diagnosis sensitively
- > Give better information at diagnosis
- > Explain what will happen next

## Management

- > Ensure rapid access to follow-up, treatment and monitoring
- > Create easy access to specialist nurses and help/advice
- > Diversify access to the specialist service
- > Join up everybody involved within PF care
- > Equip GPs and other healthcare professionals to support those with PF

## Access

- > Get the right support to people facing PF
- > Address the barriers to access
- > Condition-specific pulmonary rehabilitation
- > Mental health support
- > Dietary support
- > Oxygen therapy
- > Palliative and end-of-life care
- > Carer support
- > Social care information and support
- > Taking part in research

# Diagnosis



- 16 Fast and accurate diagnosis
- 17 Deliver diagnosis sensitively
- 18 Give better information at diagnosis
- 19 Explain what will happen next



Early, fast, and accurate diagnosis is essential to improving outcomes for PF. The progressive nature of the disease means the sooner someone is diagnosed, the quicker they can be started on disease-slowing drugs.

Despite this, many said they had symptoms such as breathlessness and persistent cough for a long time. They were often diagnosed with other serious respiratory conditions, such as asthma or COPD, before being referred for further investigations by their GP. Many don't have their chests listened to in primary care before being referred or dismissed.

Waiting times for a consultant appointment for assessment and diagnosis are too long. Many said they felt they had no choice but to opt for a private appointment to speed up their diagnosis. Others said they were diagnosed as a result of an unplanned hospital admission or following referral from another consultant, rather than being in the right place at the right time.

Even after a long diagnosis journey, waiting times for treatment are lengthy. By the time many received their diagnosis, it was too late to be eligible for treatments, such as lung transplant or anti-fibrotics, to be offered. Many highlighted that they were later told that earlier scan results had showed abnormalities, but either this was missed or a referral was not made at the time. This is neither fair nor unavoidable.

*"Mum was diagnosed too late and deteriorated too quickly to gain any true support."*

*"It took years for diagnosis because health professionals kept saying it was something else even suggesting it might be psychosomatic."*

*"Costly medication and red tape prolonged the diagnosis and the chance to take anti-fibrotic drugs. It was all too little too late."*

*"I was diagnosed in my 30s. I went to the GP several times complaining of breathlessness. I was sent away without tests and told to go to the gym."*

*"My doctor advised me to pay for initial private consultation with a consultant as NHS waiting lists were in excess of 12 months."*

**76%**

said their GP did not say they may have PF before making referral

**25%**

had symptoms for 4–6 months before seeing their GP

Being told you have a terminal illness changes your life forever. It is essential that everyone with PF is told in a sensitive but informative way.

While many people experienced caring support at diagnosis, others said healthcare professionals in clinic are very often too busy and no one was available to spend time discussing their diagnosis with them.

Too many people reported receiving their diagnosis by letter, over the phone, or via voicemail. This was sometimes given by a receptionist, or by a healthcare professional who provided little or no details about the seriousness of the condition.

People would like to receive their diagnosis face-to-face from a healthcare professional trained in breaking bad news sensitively, along with a nurse or other healthcare professional to ask about the diagnosis and digest what is usually a terrible shock. A written plan of what will happen next was also requested.

Concerningly, some people were not informed of their diagnosis and found out subsequently, such as when looking at their records in the NHS App or when asked to participate in a clinical trial. This is a shock that is simply avoidable with better communication.

*“I was alone and he just said you have IPF and that he can’t treat me even in his clinic and I should find another hospital. I left with no support and it was a Friday evening. The way I felt at that time, I was very lucky to be alive by the Monday. I felt like taking my own life.”*

*“They left a message on my phone, it was an almighty shock. Left me in a dreadful state, I fell apart. I didn’t get any support at all, appalling.”*

*“It would be helpful for someone to sit down with you and explain it, instead of using Dr Google and frightening yourself. I feel I’ve had to fight to live and for appointments.”*

**28%**

said their diagnosis could have been delivered more sensitively

**31%**

said mental health and wellbeing support at diagnosis would have made a difference

Access to information at the time of diagnosis empowers those with PF to make informed decisions about their health, treatment, and overall well-being. It plays a key role in improving their ability to cope with the challenges of the disease and enhances their overall quality of life. However, most people received no information or very little information at diagnosis, either during the consultation or in the form of written information to take home (or because diagnosis was given via letter or telephone).

Where written information was provided, it was difficult to understand due to complex terminology and abbreviations, or because they needed information in another language. Only a small proportion were referred to information provided by patient organisations, with many not aware of any sources of reliable information and support.

This left some people unsure of their diagnosis, with some not given an honest and clear diagnosis or prognosis. As a result, hours are spent searching online to understand the implications of their diagnosis and future. Online searches were frequently described as “terrifying” and “a big mistake”, with one couple saying found out the disease is terminal searching online in the hospital car park.

Some did report a good explanation at diagnosis with plenty of information and support. Notably, there was particular value in the support of a specialist nurse at diagnosis. Nurses and other healthcare professionals such as specialist pharmacists are often able to spend more time with them than the consultants explaining the disease process and their individual needs.

*“It was only when I was refused insurance six years later that I found out that it is terminal. No-one had told me.”*

*“My husband was only diagnosed through a discharge letter, nothing face-to-face for six months until a consultation with respiratory specialist. She confirmed everything we had already Googled.”*

*“The only ‘diagnosis’ my grandad got face to face was ‘you have a little scaring on your lungs’ – with no explanation into PF.”*

**3 in 4**

said their service does not signpost to the charity Action for Pulmonary Fibrosis

**Nearly half**

were not signposted to information and advice services or support

**1 in 3**

said an information leaflet at diagnosis would have made a difference

After diagnosis, many described they felt left in the dark about what would happen to them. They had received a diagnosis but no follow-up or care plan and did not understand the next steps.

Guidance about living with their condition and what they can do to self-manage symptoms is essential.

Access to palliative care teams as early as possible after diagnosis is essential. These teams take the time to find out what is important to the person affected by PF and their support network and help them to manage symptoms and live a fulfilling life.

*“It would have been really nice if someone had been able to sit down and explain it to me, as there are positive things that can be done.”*

*“No leaflets, no explanation about the way forward, what I was to do. I paid for a private appointment afterwards to help me understand exactly what was going to happen to me.”*

*“Basically feel I’ve been sent away with some drugs and that’s it.”*

*“I don’t really understand what is going to happen and when... I really suffered with my mental health being given devastating news and then nothing more from them.”*

*“I feel quite isolated and have not had any well-being discussions nor am I fully informed of what I can expect as my illness progresses.”*

# 35%

said better communication about what will happen after each appointment would have made a difference at diagnosis

# Management



- 21 Ensure rapid access to follow-up, treatment and monitoring
- 22 Create easy access to specialist nurses and help/advice
- 23 Diversify access to the specialist service
- 24 Join up everybody involved in PF care
- 25 Equip GPs and other healthcare professionals to support those with PF



# Ensure rapid access to follow-up, treatment and monitoring

## Management

There is enormous variation in care following diagnosis. People frequently waiting a very long time for follow-up and discussions about treatment, management and monitoring the condition, some people with PF opt for private care as a result.

They are particularly concerned they do not know how quickly their condition will progress and want to manage the deterioration as well as possible. This includes discussing options for treatment such as transplant and initiating these as soon as possible.

Many said they would like more regular contact with their consultant (more than every 12 months) and more regular lung function tests to monitor their progress. It is very difficult to get face-to-face appointments, or to contact their consultant or respiratory clinic. This is further exacerbated by cancellation of tests and appointments and other frustrating delays.

People on anti-fibrotic medication would like closer monitoring and more support managing side effects. For some, it may be possible to monitor their lung function at home through use of at home spirometry. However, monitoring of these results by their specialist team and access to appointments if issues appear are critical to success.

*“The treatment and frequency of appointments, scans etc, seems to be a postcode lottery.”*

*“I waited months to be seen, meanwhile my condition was deteriorating.”*

*“The progress with my case has been glacial with no person making contact in 17 months to explain where I am in medical terms or future treatment.”*

*“A two month wait to see a consultant after diagnosis without any real support and understanding of PF was shocking, and very difficult to manage my partner’s deterioration. He died before ever getting to his first appointment.”*

*“I had terrible side effects but no advice was given about handling these.”*

**8%**

waited 7–12 months to see a respiratory consultant

**45%**

were signposted to drug treatment services or information/support

**28%**

said better explanation on medication at diagnosis would have made a difference

Access to a specialist nurse is vital for comprehensive, person-centred care. Their specialised knowledge and supportive role contributes significantly to the overall well-being and experience of those with PF. When there is access to a specialist nurse, people with PF unanimously sing their praises.

Unfortunately, not everybody is able to contact vital healthcare professionals. In fact, many reported they do not perceive there to be any specialised support service for them.

Further to this, even for those with access to a specialist nurse, this role is very overstretched and there is not the capacity to give everyone the support they need for their condition. Many reported having a respiratory nurse with no specialist expertise in PF.

It can be unclear how to make contact and with whom between consultations when needing specialist advice. Some reported phone calls and emails going unanswered for days or weeks, whilst others said their nurse is contactable at any time to discuss issues.

More specialist nurses are needed to provide important information and support those with PF as well as increasing their capacity for personalised care.

*“Appointments are simply not available and there are no telephone facilities for advice.”*

*“The respiratory nurses always helpful, re zoom support groups and chasing any appointments/problems, a hugely reassuring team.”*

*“The (specialist) nurse is a godsend.”*

*“It’s impossible to speak to the nursing team and only way I mostly get responses is via email and that can take a few weeks.”*

## Nearly 50%

said they cannot always get hold of a specialist nurse when needed

Clear information is needed on how those with PF can access services. They are happy to have some services delivered remotely by phone or video call following their diagnosis which would preferably be given in a face-to-face contact.

Telephone appointments were helpful to avoid travelling which can be distressing especially for those on oxygen. If there is a 'big issue' to discuss this was deemed better done face-to-face.

People on anti-fibrotics have appointments every three months, switching between telephone and face-to-face.

There were positive comments about virtual monitoring, such as at home spirometry. Video call group meetings with a specialist nurse on different topics were deemed very useful and enabled "you getting to know people with the same condition".

Cultural sensitivity, ethnic diversity and translation services and culturally-appropriate information is essential.

*"They are usually very nice and kindly, but my appointments are frequently cancelled."*

*"I can monitor myself weekly at home now and it's wonderful. I feed the information back to the hospital team so they know I am okay. It's very reassuring."*

*"I prefer face-to-face but don't mind a video call if it's quicker."*

# 61%

are comfortable having  
some or all consultations  
by video call

Integration in the way services are currently delivered appeared limited, with variable communication between specialist services and the community. People with PF require ongoing support, yet this is hampered by gaps in joined-up care.

There were universal concerns that NHS systems do not speak to each other. Many found it frustrating that their specialist team were not able to view CT scans performed in different Trusts and state this was causing significant waste.

“Better communication between trusts and systems is needed; any healthcare professional needing access to your medical record should have it.”

Some healthcare professionals were not able to access GP records which caused delays and negated continuity of care. Those who were initially turned down for certain benefits and in need of a doctor’s letter spent weeks waiting for this.

“Doctors cannot get letters out for eight weeks – that’s a long time when you have a terminal illness.”

*“The coordination of information/medication sharing between the respiratory team and my GP is virtually non-existent. I have to explain things over and over again.”*

*“It’s difficult to understand who is actually responsible for overall IPF care. I liaise with my GP and (three hospitals). The sharing of test data is confused and often consultant meetings happen before necessary tests have been organised.”*

*“Very disjointed due to local hospital versus specialist centre. Passed on and dropped.”*

*“There is a total breakdown in communication between nurses, hospital and GP – getting a GP to sign off a prescription is a nightmare as they don’t know about it.”*

*“The last three months (of my husband’s life) was traumatic – miscommunication between all medical professionals, no joined up or consistent advice or guidance which was confusing and upsetting for both of us.”*

GPs play an important role in the everyday management of PF symptoms, treatment, side effects, and co-ordination of care.

However, many involved described challenges with their GP, frequently saying their GP is not equipped with enough knowledge or understanding to support them with the effects of living with PF. This is exacerbated by difficulties getting appointments and long waits.

People with PF would like their GPs to have more training and access to specialist information so that they can assist with monitoring their PF and to support them with their general health and comorbidities.

Regularly, people with PF tell us that other healthcare professionals do not understand the condition, and make problematic suggestions such as weaning off of oxygen, despite the fact that this would almost never be the case for people with PF. Better overall healthcare professional education of the distinct challenges associated with the severity of PF is needed.

*“No support from my GP, unable to even make appointments. Just feel I am coping alone. Nothing is ever explained.”*

*“My GP is like a rabbit in headlights.”*

*“I’m worried my GP doesn’t know enough about my condition or about the anti-fibrotic drugs.”*

*“I don’t have a specialist team, I’m just seen by my GP.”*

## Only 1 in 5

said they were signposted to their GP for services or information/support

# Access



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People coping with PF experience a concerning level of disconnection and isolation, and it is clear they need more support.

Peer support is invaluable important for those with less common conditions, as you may never meet anyone else with the same experiences. This can be provided in the form of support groups, patient organisations, peer support online or social media, which offer both emotional support and direct to information advice. While some respondents were aware of organisations like Action for Pulmonary Fibrosis, Asthma + Lung UK, and Breathe Easy, many had no knowledge of these sources of support and information.

People with PF would like referral to support groups sooner, with those accessing groups describing them as “brilliant”, “fantastic” and “feels like a family”, “the only time I feel normal”, and “you put out your hand and someone will hold it”.

Everyone affected by PF should be made aware of support groups in their area or online, as well as being referred to Action for Pulmonary Fibrosis for support and further information. People living with PF could also benefit from self-management which could be supported by Action for Pulmonary Fibrosis.

*“I feel isolated. I don’t want to be morbid but I cannot get any support.”*

*“I am struggling getting more and more cross fact of the matter is no one is giving any support.”*

*“It’s a postcode lottery around support, it’s piecemeal.”*

*“I’d have received better support if I’d had cancer...”*

**Nearly 50%**

said referral to a support group at diagnosis would have made a difference

**Only 2 in 5**

were signposted to local support group services

PF can have a huge impact on mobility. Travel to and from a specialist centre can be problematic. It is stressful to navigate travelling to hospital appointments, especially for those using oxygen and mobility aids. One couple did a trial run so they could find the hospital and prepare. Some even organise overnight accommodation in a hotel prior to an appointment because of the amount of travel involved. Many mentioned telemedicine as being more convenient.

There were perceived barriers for accessibility for advice from specialist nurses and while some have a direct line to call others did not. During the early stages of diagnosis and establishing treatment the consensus was that face-to-face consultation is better.

Rural care is not on par with those who live in a city. Many people have to make long journeys for appointments which makes for a long day out and causes concerns about oxygen supply.

Care should be provided at the nearest appropriate centre. If follow-up care and monitoring can be given in a local, more convenient hospital, then this should be made possible.

*“I have dyslexia. I cannot read leaflets. I cannot use a smart phone.”*

*“Being blind and using my guide dog can make things more difficult.”*

*“I have to pre-plan every excursion out, calculating oxygen supplies left.”*

*“I have oxygen permanently and unsure of how much I need to travel with. I ran out last time I went because it’s so far to travel. I took two cylinders and could not get anyone to help me at the hospital. Eventually someone gave me a cylinder but it’s frightening as I have to have oxygen constantly now.”*

**1 in 4**

feel their specialist service is not always accessible and inclusive

**32%**

who feel this way said it’s because of where they live

**20%**

who feel this way said it’s because of service capacity issues

Pulmonary rehabilitation is an important tool in improving the quality of life for people with PF as it provides a comprehensive and tailored approach to improving their lung function.

Those living with PF were very positive about the benefits of pulmonary rehabilitation, but it is not being offered as standard. Many reported difficulty accessing this treatment, with very long waits or the amount offered was limited. In some areas, it is only accessible once per year, whereas for others there is a supply and demand issue – some people with PF can access six weeks of pulmonary rehabilitation at the hospice but some others face long waits at the hospital.

They described doing pulmonary rehabilitation alongside people with COPD without specific support for their condition. Given the prevalence of COPD compared to PF and a lack of pulmonary rehabilitation courses, people living with PF can struggle to find space on courses. A PF-specific course would improve access and allow for specific rehabilitation for this disease.

*“The pulmonary rehab course is the best thing I ever did. You can do a lot more than you thought.”*

*“Pulmonary rehab not offered, I had to pester. I used to walk 2,000 steps a day, now I do about 40 or 50.”*

*“It feels like it finishes too soon, just when you’re getting the hang of it, you’re left on your own.”*

*“I went on the waiting list for pulmonary rehab and then when my turn came I was told (my condition) was too bad for it now.”*

## Almost two thirds

were not signposted to pulmonary rehab services or information/support

Receiving a terminal diagnosis can have profound and varied effects on mental health. Prioritising mental health support alongside medical care ensures a more holistic and compassionate approach, enhancing the overall quality of life for individuals coping with a PF diagnosis.

Those involved describe PF and the uncertainty that comes with it as being very difficult to cope, reporting depression, anxiety, lack of motivation, isolation and lack of peer support. There was an overwhelming desire for better condition-specific mental health support.

People with PF feel listened to by their specialist teams and speak of receiving help with emotional wellbeing from their PF nurse. NHS Talking Therapies services were not viewed as suitable.

Unwarranted variation in mental health services was apparent and the underlying anxiety that develops means those affected isolate themselves and retreat from daily life (exacerbated by issues with oxygen supplies or cylinder portability). Many said their lifestyle had changed dramatically.

Support groups were cited as incredibly valuable as were palliative and Marie Curie services which gave psychological support. Care navigators and social prescribers were very helpful where available.

*“I had to fight for a referral from my GP to see a psychiatrist.”*

*“I got no help where I lived before, but here I got specialist respiratory mental health support. There should be the same level of help across the board.”*

*“I’ve had NO support whatsoever... I got help off my own back, I had a breakdown last year.”*

*“People can’t see this illness. They say you look well but they don’t know how you feel inside.”*

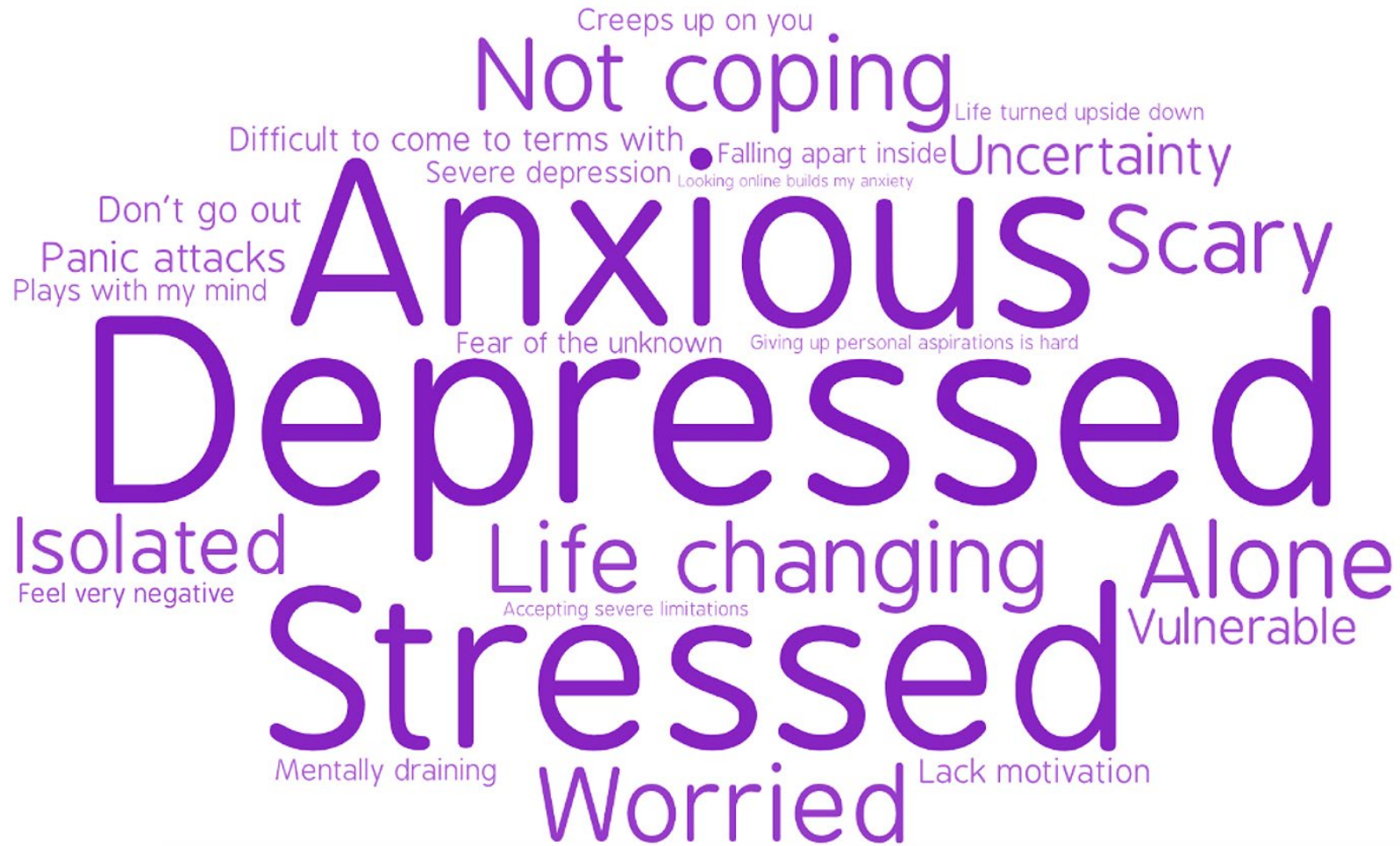
**1 in 3**

said mental health and wellbeing support at diagnosis would have made a difference

**Almost 90%**

have not received support from a mental health practitioner since diagnosis

Key words used by people with PF to describe the condition's impact on their mental health.



People with PF often experience symptoms such as shortness of breath, fatigue, and a reduced ability to engage in physical activities. These symptoms can contribute to a decrease in appetite and an overall decline in energy levels.

The subject of diet came up frequently in the focus groups. Many highlighted that low appetite is a real problem for them and they would like more support with their diet. Help optimising weight and nutrition is particularly important for lung transplant.

Ensuring an appropriate diet is a concern for carers too. People want advice on finding suitable high-calorie foods that are high in protein and manageable for them to eat (moist, for example). This could be via access to a dietician, information packs or as a PF support group discussion topic.

*“I have no interest now in food, I’ve lost six stone since I developed this.”*

*“Lack of nutritional advice is an issue. Antifibrotics caused significant gastrointestinal effects; there was no discussion on what I could and should eat or advice on high calorie foods.”*

*“(We need a) back up phone call when put on medication to see how you are getting on. I was left and lost a lot of weight in a short time which made me poorly.”*

*“My mouth is always dry, it causes considerable discomfort. I wake with my tongue stuck to the roof of my mouth.”*

PF involves inflammation and scarring of the lung tissue, leading to reduced lung function and impaired oxygen exchange. Oxygen therapy is essential to help maintain oxygen levels and relieve breathlessness.

Obtaining oxygen supplies is a postcode lottery, with supply issues causing major problems for some. Availability of oxygen has a substantial impact on day-to-day life and can mean people are frightened to leave their house for fear of running out, and the difficulty managing the heavy weight of oxygen cylinders, leading to isolation.

Some people described the relief of having a portable oxygen concentrator which is much lighter. However, having enough battery life to last is still a concern. Grants for spare batteries are available but not well publicised. Trying to manage the oxygen needed for the length of time spent out is stressful. Delays and challenges exist when ordering supplies.

Many people also reported very good experiences with oxygen services, with straightforward ordering, quick delivery and no supply issues. One person said their care team visited three times a week when they first started oxygen and still come regularly to check everything.

*“Being on oxygen is bad enough, but it’s so stressful worrying if you have enough to last. It restricts how often you can go out.”*

*“I live in fear of running out.”*

*“I was advised to order double in case of running out but the company has a restriction on how many cylinders I can have.”*

*“My oxygen was not delivered and as a result I was admitted to hospital for a week.”*

## Two thirds

were not signposted to oxygen services or information/support

PF and its treatments come with a range of symptoms and side effects, many of which can be increasingly debilitating. People with PF should be on their GP's supportive and palliative care register to ensure they are offered enhanced services.

Palliative care teams get to know those with PF, understand what is important to them, and help them to manage their symptoms and live the best life possible following a diagnosis.

Those with a life-limiting form of PF also highly value early referral to supportive and end-of-life care, describing excellent care offered by hospices and palliative care services.

The benefits mentioned included having a new lease of life, with new possibilities and the ability to perform activities which they thought were no longer possible, such as gardening.

The main issue with access to palliative care for people with PF was recognition by community services that it was needed. Only 9% of the those who responded to the survey had been referred. More work needs to be done on the local and regional level to improve joined-up care between specialist palliative care teams and community services.

*"My dad got very little help in the last 12 months of his life."*

*"I have recently been able to access more services after being referred to a hospice and this has helped a lot."*

*"My husband received excellent end-of-life care. He lived with IPF for just over a year."*

*"The hospice was initially very good but we couldn't keep going because they didn't provide ongoing palliative care when they realised he wasn't dying. They only do end-of-life care for non-cancer diagnosis."*

# 9%

were signposted to advanced care planning or end-of-life services or information/support

The burden on friends and family is significant and carers know they will need to do more and more as the condition progresses. Many carers reported struggling to cope with their responsibilities, seeking out support in the form of support groups – which many described as very important and motivating for them.

Others have been prescribed antidepressant medication by their GP. Many are scared they will get ill and anxious to keep themselves well.

*“You’re caring for a different person, personalities change drastically.”*

*“He feels alone and scared and I am scared too; its awful to live with this, we are waiting and waiting. We were told life expectancy of 18 months to three years.”*

*“No thought for carers – we were at breaking point not knowing what to do.”*

*“It’s hard to care for someone who keeps saying ‘I won’t be here this time next year.’”*

As PF progresses, the stresses on home life and finances can grow. More help is required to improve understanding the social care support that is available to them.

The benefits system can be a minefield and there was a clear theme of confusion about what those with PF are entitled to claim and difficulties with the process.

There was a clear value of the support offered by organisations that help navigate these aspects of living with their condition, such as those offered by Citizens Advice Bureau, Action for Pulmonary Fibrosis, Step to Change and local PF support groups. This allowed them to access vocational rehabilitation, singing therapy, Tai Chi, mobility scooters and blue badges for accessible parking.

*“Some real professional guidance from point of diagnosis would have been really helpful to navigate this process. It’s hard enough being given this life changing diagnosis without have to fight for entitlements.”*

*“My wife was taken to the ICU when she became ill. At no time did any consultant tell me what was going on and what we could do, including getting financial support.”*

*“Not enough is done regarding benefits. Patients shouldn’t have to fight for what they are entitled to.”*

*“I got in touch with a private therapist because I was pretty freaked out. She was great. But it’s expensive and I have no income because I can’t work now, but I’m too young for a pension, and I have too much savings to get benefits.”*

# 94%

were not signposted to home care/assistance services or information/support

Patients are motivated to take part in research to help others, find better treatments, learn more about their condition and raise awareness of pulmonary fibrosis.

People with PF want to learn about opportunities to participate in research, including studies testing potential new treatments and research that aims to improve living with or monitoring the disease.

Despite numerous research studies taking place in the UK, there are many barriers for patients to get involved. Only 1 in 3 patients reported being asked if they wanted to take part. Often patients try to enrol on a study, only to be told they do not meet the strict inclusion criteria. Clinical trials tend to be carried out at specialist centres, leading to inequitable access. For many patients, the burden of travel to a trial site is too great.

Patients desperately need access to faster diagnosis, better treatments and care. Research can make this happen.

*“I declined taking part in research as there are no local check up facilities – travelling to Birmingham was necessary.”*

*“I would like to see more research being done and more awareness created of the disease as when I have told people of my diagnosis hardly anyone has heard of it!!”*

*“Seven people in my family have had it, research is key – who knows, in 10 years things may be different for those diagnosed with this awful disease!!!”*

*“I would be willing to take part in trials but it has never been spoken about.”*

## Only a third

said the possibility of taking part in research had been discussed with them

# Transforming PF care for good

What's next?

We are incredibly thankful to everyone affected by PF who took the time to share their experiences for this report.

Data and testimonies like these are essential to creating change. Decision-makers in government cannot ignore the themes brought out through the survey and the many interviews.

Action for Pulmonary Fibrosis recently held its first event in the Houses of Parliament, and this data shows everyone in the corridors of power that action is needed to improve PF care.

This information has already helped to inform the new national integrated care pathway for interstitial lung disease. The pathway sets out a vision for the future of PF care, ensuring that the postcode lottery across the UK for diagnosis, treatment, and care of PF ends for good.

In the coming months, using this data as the base, we'll be looking to influence NHS bodies to implement the pathway in their areas.

Further to this, we will be **calling on the NHS to implement a timed pathway for PF.**

Being diagnosed and starting treatment earlier gives the best chance of living better for longer. Cancer services make the most of this by having a timed pathways from suspected diagnosis to starting treatment which must be met.

Despite having similar outcomes, this is not the case for PF. This information will be a key source of evidence in calling for this change.

Action for Pulmonary Fibrosis will continue to stand up for PF patients, and this piece of work will help us to influence those in power to make serious transformational changes.



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

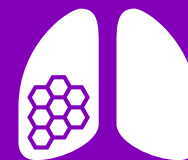


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