

Your essential caring guide

Support and advice for carers of people living with pulmonary fibrosis

This booklet was produced as a collaboration between Action for Pulmonary Fibrosis and Boehringer Ingelheim Limited. Boehringer Ingelheim Limited provided funding and support, with organising and project management in line with the ABPI and IPHA Code of Practice. Action for Pulmonary Fibrosis provided carer insight and guidance.

Introduction

Action for Pulmonary Fibrosis (APF) is a national patient-driven charity. We support and campaign for anyone affected by pulmonary fibrosis, while funding research into treatments and a cure.

This guide was produced by Action for Pulmonary Fibrosis and Boehringer Ingelheim, in consultation with current and past carers. We would like to thank all the carers and patients who have kindly contributed to its creation.

Caring for someone with pulmonary fibrosis can be challenging at times, but it isn't something you have to navigate on your own.

Fortunately, there's a lot of help out there – from practical advice to emotional support – and this booklet is here to help you find it.

This booklet will help you find the organisations and networks who can support you, every step of the way. It's also full of practical advice and useful insights from experienced carers who can guide you through some of the possible challenges.

“Never be afraid to reach out and ask for help. Carers are going through the same journey as the person with pulmonary fibrosis, we just get off at different stops.” Carer

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Caring for someone with pulmonary fibrosis

Diagnosis and what it means

Pulmonary fibrosis is a lung condition that causes scarring of the lung tissue, making it harder to absorb oxygen and effectively distribute it throughout the body.

Symptoms can vary from person to person, but commonly include:

- Shortness of breath
- Persistent cough that may get worse during day-to-day activities
- Widening of the fingertips (finger clubbing), caused by lack of oxygen
- Tiredness
- Weakness
- Loss of appetite
- Weight loss

Three things to know about pulmonary fibrosis

It's restrictive, causing scarring in the lungs, making it hard for them to expand and absorb enough oxygen.

It's unpredictable, progressing at different rates for different people. Some may remain stable for long periods while others may deteriorate rapidly without warning.

It's permanent, causing irreversible lung damage, although some treatments may slow down the progression of the damage.

Acute exacerbation

This is a sudden and severe worsening of symptoms. It is essential to contact your medical team immediately if any of the following symptoms develop or get worse:

- Difficulty breathing (requires more effort than usual)
- A cough that gets worse
- Fever or flu-like symptoms (e.g. body aches)

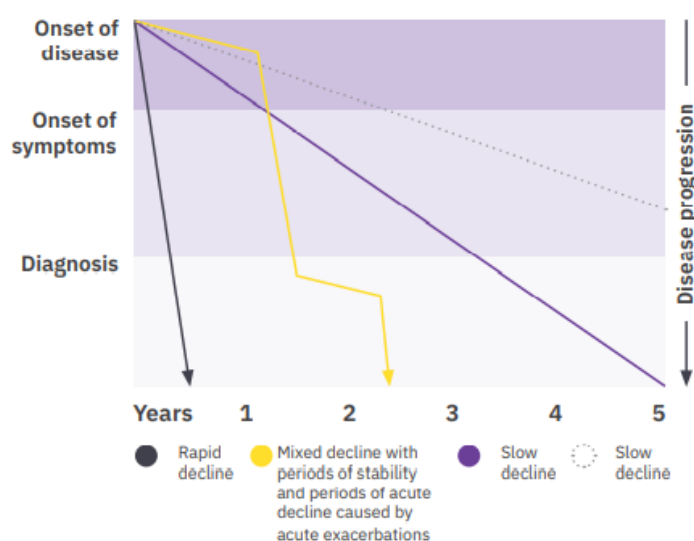
Not everyone with pulmonary fibrosis will experience an acute exacerbation, but if they do, it can be serious and they may need hospital treatment.

“Learn as much as you can about the disease to enable you to give the best possible support. No question is too small or trivial with this disease, due to its complexity.” Carer

Managing expectations

There is currently no cure for pulmonary fibrosis, so generally symptoms will get worse over time. But how fast the disease progresses varies from one person to another, and we don't know why this is. In the past, most people diagnosed with idiopathic pulmonary fibrosis (IPF), a common type of pulmonary fibrosis, typically had a life expectancy of 3-5 years.

Nowadays, right from diagnosis, appropriate treatments are available for eligible patients that can control symptoms and may slow down decline.



If you're caring for someone, it helps to know their usual symptoms, so you can recognise early when things are starting to worsen. To help you do just that, you'll find some useful information later in this booklet about planning ahead and anticipating changes; doing this can really help to minimise stress and improve wellbeing.

Enjoying the best possible quality of life

"I keep as fit as I can and go to the local gym. You just keep going really, leading as normal a life as possible." Pulmonary fibrosis patient

Caring for someone with pulmonary fibrosis isn't always easy. You may have to adapt to changes that can seemingly happen overnight, while preparing for other changes ahead. It's useful to do as much planning as you can early on, so you can then focus on living life as fully as possible.

Healthy lifestyle

Both you and the person you care for will benefit from a healthy, balanced diet with plenty of fruit and vegetables. Instead of eating three larger meals, it might be better to plan four to six smaller meals throughout the day. It's a good idea to watch out for changes in their weight and report any worries you have to the medical team.

Physical activity and exercise

The benefits of regular physical activity or exercise can't be underestimated: it helps maintain muscle strength, improves sleep, reduces stress and improves wellbeing for you both. However, exercise can seem daunting for anyone living with pulmonary fibrosis, who may be out of breath before they even start. Start gently and gradually build up as their strength increases. Even a regular short walk will be beneficial and you can gradually increase the distance as their confidence and strength grows.

Smoking

If you're caring for someone who smokes, encourage them to discuss ways to stop smoking with the medical team or pharmacist. If you're a smoker yourself, it may be a difficult time to stop, but there are plenty of helpful strategies out there if you do want to try.

Some useful tips to get you started

There's no one-size-fits-all approach to being a carer. What works for some might not work for everyone. But if you're having to adapt to change fast, these tips might help you settle into your role.

Prepare meals in advance

If you're doing most or all of the cooking, you might not have the time and energy to prepare a meal every day. Consider preparing meals in advance and freezing them to reheat later. If the person you care for feels tired later in the day, it can help to plan mealtimes for a bit earlier.

Keeping the home clean

This is important, especially for someone living with a lung condition, but avoid using strong smelling cleaning products, air fresheners and heavily fragranced candles, which could irritate the lungs.

If some extra help would be useful, AGE UK may be able to assist with their home help service: <https://www.ageuk.org.uk/services/in-your-area/home-help/>

Limit exposure to dust and irritants

It can be beneficial to vacuum and dust regularly. Keep an eye out for any damp spots that could get mouldy, such as bathrooms, air conditioners and refrigerator drip pans.

Reduce the risk of passing on an infection

Regular hand-washing and sanitising reduces the risk of passing on infections such as cold or flu. It's also advisable that you and the person you're caring for get the annual flu vaccine and one-off pneumonia vaccine ahead of the colder months, and the COVID-19 vaccine, if you haven't already. Consult your medical team to check vaccine suitability.

Help the person you're caring for stay cool during warmer months

For someone living with pulmonary fibrosis, excessive heat can make breathlessness worse. Try to keep the house cool during warmer weather by opening windows and using fans but try not to make it too cold at home (cool temperatures may equally influence symptoms). During particularly hot days, it might be best to let the person in your care stay at home. Sunscreen is also key as some of the medicines prescribed for pulmonary fibrosis can increase sensitivity to sunlight.

Therapies that can help

While there is no effective cure for someone living with pulmonary fibrosis, there are a number of ways to help the person live a normal life for as long as possible. The medical team may discuss some of these options with you and the person you're caring for.

Symptom management (palliative/supportive care)

'Palliative care' is often associated with end of life, but this symptom management programme can help much earlier than that. Both you and the patient can get support with all aspects of care (called 'holistic care'), including pain relief, physiotherapy, complementary therapy and counselling, as well as advice on benefits and financial support. Above all, palliative care improves quality of life for you both, and you'll find this support from local hospices. Your GP or district nurse should be able to connect you, or you can contact your local hospice directly.

Oxygen therapy

You may be given a device that delivers oxygen to the lungs, increasing the amount of oxygen that travels through the blood and to other parts of the body; this helps to preserve the vital organs. This therapy may help to improve tiredness, sleep and mobility, while potentially lowering blood pressure.

Pulmonary rehabilitation

Pulmonary rehabilitation is a programme of tailored exercise and education, helping people with lung conditions manage their symptoms and lead a more active lifestyle. The aim is to help them cope with their breathlessness and feel fitter and stronger. It can also help improve mood and wellbeing and give people greater confidence in managing their condition, enhancing quality of life.

Lung transplantation surgery

Transplantation is a procedure that replaces lungs affected by the condition with healthy lungs from a donor. This could increase both the span and quality of life. However, to be placed on the lung transplant waiting list, each person with pulmonary fibrosis has to meet certain criteria, and not all patients will be suitable.

Pulmonary fibrosis treatment

These medicines can help slow down the rate at which the condition worsens. The doctor will be able to help decide if any of these medicines are a suitable option and how to manage any potential side effects.

What the doctor needs to know

If medication for pulmonary fibrosis is agreed, before the person you're caring for is about to start treatment, it's important that the medical team know about any other medication or treatments they are on. Examples include prescribed medicines, over the counter drugs, vitamins and herbal supplements.

Side effects and how you can help

When specific medicines for pulmonary fibrosis are prescribed, some people can experience side effects. Not everyone gets them, and experiences vary from person to person. The type of side effects may also differ depending on which medicine is taken. You'll find more information about these medicines and their side effects in the Patient Information Leaflet included with the medication pack, or on www.medicines.org.uk/emc

Here are some common side effects experienced by people taking medicines for pulmonary fibrosis:

- Diarrhoea • Nausea (feeling sick) • Vomiting • Stomach upset, feeling constipated or indigestion • Weight loss • Decreased appetite • Abnormal liver test results (the person you're caring for will be having regular blood tests to keep an eye on this) • Difficulty sleeping • Tiredness • Dizziness • Headache • Throat infections or sinusitis • Shortness of breath • Cough • Aching joints/ joint pains • Rash • Photosensitivity reaction

It's really important that the medical team knows about any other medicines the person you're caring for is taking, as these may also be contributing to side effects. If the person in your care does get any side effects, make sure they talk to their doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. They can also report side effects directly via the Yellow Card Scheme at www.yellowcard.mhra.gov.uk. By reporting side effects, they can help provide more information on the safety of medicines.

It helps to keep a note of any side effects that you observe and to share these with the doctor at the earliest opportunity. They can advise on remedies or other ways to manage the side effect. As treatment plays a significant role in managing pulmonary fibrosis, encourage the person you're caring for to take their medicine as prescribed, unless the doctor specifically tells them otherwise.

Getting the most out of consultations

The person you're caring for may start to rely on your support during doctor's appointments, especially if they're experiencing fatigue, anxiety or depression. If possible, attend as many of these appointments as you can, and come prepared so you can get the most out of that time. If you are appointed a Lasting Power of Attorney, this will enable you to act on their behalf when communicating with health care professionals. You can find out more about the Lasting Power of Attorney process on **page 11**.

Here are some things you can do to get the most out of a consultation with the medical team:

Write down any questions in advance of the meeting (you can find a notes section for this at the end of this guide).

Write down any particular topics you would like to raise, such as side effects, changes in symptoms or moods, or any upcoming plans you have with the person you're caring for (such as going on holiday).

Take notes during the appointment, especially if you know the person you're caring for might have trouble remembering some things afterwards.

Ask for additional pamphlets, brochures or support materials if you haven't already been provided with any and require more information. There are plenty of guides available for both you and the person you're caring for – this booklet is just one of them. It's always best to rely on information you have received from the medical team, which is accurate and relevant to your individual circumstances.

"Make sure you get all the questions answered before you leave, so that you haven't got any worries afterwards." Carer

Make sure you know who you can follow up with if you do have any questions after the consultation. You may not be able to contact the doctor directly, so if it's their secretary or the nurse you should be reaching out to, ask for their contact details and what times they are available to talk. For emergencies, always contact the hospital. There is a section at the end of this guide where you can note down any contact details for people such as the respiratory nurse, physiotherapist, occupational therapist, district nurses, etc.

Help is out there for you, too. You don't have to do this alone.

"People with pulmonary fibrosis do get depressed and touchy and take it out on us. That's when you need to reach out to others. You can't do it alone." Carer

The signs of anxiety and depression

It's common, and perfectly natural, for people with pulmonary fibrosis to feel anxious or depressed, or both. Of course, all too often, this applies to their carers too. Dealing with a disease that makes it difficult to live life to the full can be tough. If you or the person you're caring for feels this way, don't suffer in silence:

- Reach out to community or online support groups
- Ask a doctor about medicines that may help
- Learn about depression and anxiety

Symptoms of depression can include:

- Low mood lasting two weeks or more
- Feeling hopeless
- Comfort eating or loss of appetite
- Sleeping more than usual or being unable to sleep
- Having suicidal thoughts

Symptoms of anxiety can include:

- Feeling worried or uneasy a lot of the time
- Being irritable
- Feeling tearful
- Breathing faster
- Palpitations (an irregular heartbeat)

Self-care is key to caring for others

As a carer, it's important that you look after your wellbeing and try to keep yourself fit and healthy. In the section titled 'Looking after yourself' (**page 12**), you'll find lots of information which will help you to take good care of yourself.

Thinking ahead

"We make every day count; we spend quality time together, we try to laugh, we talk a lot, we make plans..." Carer

To provide the best possible quality of life and care provision, it's important to plan ahead to manage change as effectively as possible. The practical steps you take now to make life easier in future will help to ensure you have quality time together and have one less thing to worry about.

Lasting Power of Attorney for health and wealth (LPAs)

You can be appointed an attorney (along with someone else) depending on the wishes of the person you are going to be caring for. There are two types of LPAs: Health and Welfare, and Property and Financial Affairs.

These LPAs can give you, and any others appointed, the power to make decisions about medical care and financial affairs and come into effect if the person in your care loses mental capacity, or no longer wants to make decisions themselves. These can be arranged in advance to make sure they're covered in the future.

Once registered (which may take time) you can use these powers immediately or they can be held until required. Application packs are available from:

Office of the Public Guardian PO Box 16185, Birmingham, B2 2WH

or via phone on: 0300 456 0300

or email: customerservices@publicguardian.gov.uk

You can find more information about LPAs and the application process on:

<http://www.gov.uk/power-of-attorney>

<https://www.nhs.uk/conditions/end-of-life-care/lasting-power-of-attorney>

Home adaptations

Home improvements and adaptations such as stairlifts, walk-in showers, handrails, and changing access to the home, can be put in place before necessity sets the pace, saving unnecessary stress and making life less difficult. If you live in the UK, your local council can offer a service that assesses your home for free and recommends changes.

Oxygen therapy considerations

In the future, the person you're caring for may need oxygen therapy. Where will you put the equipment and where can you obtain it? It's worth thinking about the answers to such questions in good time. If you want to know more about oxygen therapy, you can ask your medical team for more information and there is an overview on

<https://www.nhs.uk/conditions/home-oxygen-treatment/>

Palliative/supportive care

As mentioned previously, palliative care is not just for end of life. For people with pulmonary fibrosis it can ease pain, improve quality of life and increase comfort. One way a palliative care team can help you to plan ahead is by providing expert advice on how to have difficult conversations with family members, including preparing for issues arising towards the end of life.

“Think ahead for what you may need for general living conditions before you are in a position to need them desperately.” Carer

Day-to-day living

On a day-to-day level, planning ahead can make every day better. For example, if you're planning a trip out with the person you look after, are there any hills? Where are the toilets? Will you need to bring equipment or medication with you? Anticipating issues before they arise can help.

Holiday planning

If you're planning to go on holiday together, consider how manageable the journey will be and whether you can get help with luggage and transfers. Can you both cope with the altitude, weather or any rough terrain at your destination? If you're thinking of flying, discuss this with the medical team as soon in advance as possible.

You may need to arrange a supply of oxygen at your destination – the home oxygen supplier should be able to provide this in the UK or Ireland, or advise you about hiring oxygen overseas. You will need full travel insurance, printed or stored copies of medical information, your UK Global Health Insurance Card and insurance details (if you have a European Health Insurance Card, that may also still be valid in some countries). Look out for expert travel agents who specialise in accessible/disabled travel, and get advice from disability websites such as www.disabilityholidaysguide.com

Looking after yourself

“It's OK to have a bad day. Be kind to yourself.” Carer

As a carer you may feel that you should be able to cope with anything that comes your way – but that's absolutely not true. Everyone has good days and bad days, and you are no exception. So try to be kind to yourself.

Sometimes caring can feel lonely. Keeping up a brave face for the person you're caring for can be wearing, especially if you're not feeling 100% yourself. Feelings of frustration, anger or guilt are normal and to be expected.

Working while caring

There is no one perfect solution for caring for someone while you are working. Take time to think about what support is right for you. It may help to explain the issues you are facing to your employer, so that they are aware of the situation if you experience problems or need time off for doctor appointments or emergencies. You may also be able to discuss

flexible ways of working, such as working from home or changing your work hours.

Financial support for you

If your situation is such that you have to become a fulltime carer for someone and you live in the UK, you may be entitled to Carer's Allowance. Carer's Allowance is a benefit paid to anyone who is looking after someone for more than 35 hours a week. To find out how to claim a Carer's Allowance, visit www.gov.uk/carers-allowance

If you look after someone for more than 20 hours a week and don't get Carer's Allowance, you may be eligible for Carer's Credit instead. To find out more, visit www.gov.uk/carers-credit or <https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/carers-allowance/>

How to avoid 'carer burnout' or 'compassion fatigue'

If you are feeling sad, angry, or unable to sleep most of the time, you may be experiencing something called 'carer burnout' or 'compassion fatigue'. This is when the challenges of providing care become overwhelming and your mental attitude can become negative, sometimes to the point of depression. If you are feeling very down most of the time, it is very important to speak to a professional about your feelings.

Many people in a caring role can benefit from counselling, especially if you feel the impacts of caring are affecting your mental health. If you live in the UK, you may be able to get counselling free on the NHS. A GP can refer you, or if you live in England, you can refer yourself directly to an NHS therapies service without a referral from a GP. Visit www.nhs.uk/service-search/mental-health/find-apsychological-therapies-service to find out more.

It's ok to accept help from family and friends

If people want to help, you can ask each person to help with a task that matches their skills. If you have a friend who is a good cook, ask that person for a homemade meal. If another friend is handy with repairs, ask them to fix things around the house.

"Reaching out is important. You can't do it alone." Carer

Carers' breaks and respite care

If you are worried that you cannot provide enough care, talk with the person you are caring for and other family members. In some cases, a nursing home or assisted living facility may be the best option, at least temporarily. These services may not be available in all parts of the country, so it's best to contact your local council or a local carers' centre to find out if there is any support in your area.

Taking time out and accessing hospice care

Everyone needs a break now and again, so hospices play a key role in providing respite care, medical support, and a range of therapies for patients, families and carers. Ask your doctor about the hospice care available to you locally. You don't always have to be referred by a doctor; some hospices accept self-referrals, so you may like to contact your local hospice directly to see if they can help.

Respecting final wishes

Discussing someone's final wishes, especially if it's a loved one, can be difficult – but having these documented in an advanced care plan can give you both peace of mind. That way, you can put all the things you need to in place and focus on making the most of your precious moments together. You may want to discuss funeral arrangements or wills. Your support network or palliative care team will be able to support you in navigating these conversations.

You are not alone

"Friendship, trust and a cup of tea (real or on Zoom) make a real difference to how we feel." Pulmonary fibrosis patient

Finding the support you need

A pulmonary fibrosis diagnosis can be very difficult to deal with. Friends and family may not understand what you're going through. You don't know what the future holds, and you may not know where to turn for help.

Thankfully, support comes in many forms. You and the person you're caring for may be offered support by friends and family; and other support is there if you just ask for it, from the organisations listed on the following pages. Talking to people who understand what you're going through can really lighten your load.

Support groups and organisations

There are support groups for both patients and carers (many welcome both) and they can be a huge comfort and inspiration. They provide emotional support, information, practical guidance, and advice on where to get help when you need it.

Encourage the person you're caring for to join a patient support group. It can really help to meet people in the same boat, who understand all the challenges of pulmonary fibrosis. Some may be further on the journey and can help you think ahead.

Specific support groups for carers can provide a wealth of benefits, including relief from loneliness, emotional support and friendship from others going through similar experiences, and practical support for all aspects of caring for somebody with a serious illness. These groups also provide an opportunity to learn about coping strategies that may work, and a way to share knowledge and advice. You can search a local group here: www.actionpf.org/information-and-support/find-a-support-group

Befriending services may feel more appropriate for you where you will be matched with someone in a similar position to you. Action for Pulmonary Fibrosis can also link you with a carers' group and a listening ear via telephone befrienders, who have personal experience of pulmonary fibrosis as carers or patients.

You may also find it helpful to contact organisations (such as Samaritans) which focus on supporting your mental health.

If you know other carers, you could set up your own support network. You could use messaging apps to create group conversations to share tips and support. Just be careful when disclosing any personal details online.

You can also watch a webinar about personal experiences of caring for someone with pulmonary fibrosis. Fellow carers shared their personal experiences and answered questions from a live audience. To watch the webinar type this website into your browser: www.bit.ly/talkingPF

"I wish I'd had contact with a carer from the word go... somebody who's been down that road, somebody that can say look, it's very daunting, but I can help you." Carer

Useful contacts and networks

Support for carers

UK

Action for Pulmonary Fibrosis (APF) - Carers' Support Group

Website: www.actionpf.org

Monthly group run by and for carers of anyone living with pulmonary fibrosis. Visit www.actionpf.org/informationand-support/support-line for contact details, or email supportline@actionpf.org for more information.

Carers Trust

Website: www.carers.org

They can help you find carer support in your area, just enter in your location in the search bar on www.carers.org/help-and-info/introduction

Carers UK

Website: www.carersuk.org/home

Helpline: 0808 808 7777

Email: advice@carersuk.org

IRELAND

Family Carers Ireland

Website: www.familycarers.ie

Careline: 1800 24 07 24

"They're there to help and support in any way and that's for the whole family." Carer

The following organisations are for people affected by pulmonary fibrosis, but may also offer specific support for carers.

UK

Pulmonary Fibrosis Trust (PF Trust)

Website: www.pulmonaryfibrosistrust.org

Emotional and practical support: 01543 442 191

Asthma + Lung UK

Website: www.asthmaandlung.org.uk

Support line: 0300 222 5800 Support group information:
helpline@asthmaandlung.org.uk

Scleroderma & Raynaud's UK (SRUK)

Website: www.sruk.co.uk

Support line: 0800 311 2756

National Rheumatoid Arthritis Society (NRAS)

Website: www.nras.org.uk

Support line: 0800 298 7650

British Sjögren's Syndrome Association (BSSA)

Website: www.bssa.uk.net

Helpline: 0121 478 1133

Sarcoidosis UK

Website: www.sarcoidosisuk.org

Schedule a call from the Sarcoidosis UK nurse helpline via the contact form on the website, or call 020 3389 7221 to request a call back.

Chest Heart & Stroke Scotland (CHSS)

Website: www.chss.org.uk/chest-information-and-support

Advice Line Nurses: 0808 801 0899

Northern Ireland NI Chest Heart & Stroke

Website: www.nichs.org.uk

You can contact their support services via the contact form on the website and they'll contact you for an initial chat.

IRELAND & EUROPE

Irish Lung Fibrosis Association (ILFA)

Website: www.ilfa.ie

You can contact their support services via the contact form on the website.

The Irish Lung Health Alliance

Website: www.lunghealth.ie

Irish Thoracic Society

Website: www.irishthoracicsociety.com

Arthritis Ireland

Website: www.arthritisireland.ie

EU-IPFF (European Idiopathic Pulmonary Fibrosis and Related Disorders Federation)

Website: www.eu-ipff.org

European Lung Foundation

Website: www.europeanlung.org

Charities dealing with mental health

Rethink (UK)

Website: www.rethink.org Helpline: 0300 5000 927

Mind (UK)

Website: www.mind.org.uk Helpline: 0300 123 3393

Samaritans (UK & Ireland)

Website: www.samaritans.org

Helpline: 116 123 Email: jo@samaritans.org In a mental health crisis, contact your GP during work hours, call 111 or go to A&E out of hours.

Palliative and supportive care

Hospice UK

Charity working to ensure the best possible care for anyone at the end of their life.

Website: www.hospiceuk.org

Telephone: 0207 520 8200

Hospice care finder

A handy way to search for your nearest hospice – just pop in your postcode: www.hospiceuk.org/hospice-care-finder

Questions for the medical team

Use this page to jot down any questions you have about your role as a carer or caring for someone with pulmonary fibrosis

Question

Answer

Question

Answer

Question

Answer

Question

Answer

Question

Answer

My local contacts:

Respiratory nurse:

GP:

District nurses:

Hospice/Hospice at home:

Palliative care team:

Occupational health:

Physiotherapist:

Local support group contact:

Others:

“No question is a silly question, and we need as much information as we can get, so that we can cope better.” Carer

Across the country, thousands of carers look after loved ones with pulmonary fibrosis. Never be afraid to ask for help. We are here to support you to look after yourself, so that you can look after others.

If you need information or advice on living with pulmonary fibrosis, we are here to help. The Action for Pulmonary Fibrosis support line can provide you with information and advice.

Please visit www.actionpf.org/information-and-support/support-line for contact details and more information.

Alternatively, you can email supportline@actionpf.org

General enquiries

01733 475642 info@actionpf.org

www.actionpf.org

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