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If you've been diagnosed with pulmonary fibrosis, including IPF, this self-management plan can help you take care of yourself and feel more in control.

Choose the pages you feel will help you. You might want to take this booklet with you to appointments with your healthcare professional. You can also share this with your family, carers and friends.

# About you

This plan belongs to:		
First name:		
Surname:		
Telephone:	Mobile:	
I have been diagnosed with:		
Allergies:		
Dates of last vaccinations (flu, pneumonia, coronavirus):		
I have these other conditions:		
In case of emergency, please contact:		
First name:		
Surname:		
Relationship to you:		
Telephone:	Mobile:	
Email:		
My doctor is:		
1		

At: (Name of the clinic or hospital where your doctor works) Telephone:

### **Other contacts**

You can put the contact details of other people you may need to contact on this page.

For example:

- a specialist nurse, GP, pharmacist or physiotherapist
- an out-of-hours clinic or emergency contact
- a friend, neighbour or family member you can call on for help
- a transport provider or taxi firm you use to get to your appointments.

Contact	Name	Telephone

# My appointments

Keep track of all your appointments with your GP, nurse, specialists and others. You should also record home visits and remote consultations.

Appointment date:
Meeting with:
Tests I had:
My results were:
What they told me/notes:
Questions I want to ask:

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# My treatment

Keep track of your treatment – things like medication, pulmonary rehabilitation and oxygen.

#### Name of medication or treatment:

Date started:

Details (for example, how often, when, dose, side effects):

Date ended:

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Date started:

Details (for example, how often, when, dose, side effects):

Date ended:

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Date ended:

**Tip**: Set reminders on your phone or in a calendar so you don't forget to take your medication.

# My diagnosis

#### I was given my diagnosis by a multidisciplinary team:

This means a group of expert healthcare professionals discussed and agreed your diagnosis, rather than just one individual healthcare professional. This is recommended for diagnosing pulmonary fibrosis.

#### What I've been told about my diagnosis (include the dates):

For example, the name of your condition, likely treatment plan, what your condition means

Questions I want to ask:

# My checklist

Your specialist team can help you feel better and improve your quality of life. Discuss these options with your healthcare professionals regularly to see what meets your current and future needs:

If I smoke, I'm offered help to stop

Staying up to date with vaccinations: flu and coronavirus. I'm also offered the one-off pneumonia vaccine

Getting information and support from a specialist nurse

Information about support groups

Being referred to pulmonary rehabilitation (PR)

Medication to help my symptoms, and being referred to support services (like palliative care services) to help with and give advice about difficult symptoms

Information about oxygen therapy and being referred for oxygen assessment

Medication to slow the scarring in my lungs

Regular follow-up appointments

Current research programmes that are relevant to me

Information about lung transplant and being referred for transplant assessment

# My flare-up plan

Sometimes, even if your health has been stable, your symptoms may flare up. This is called an acute exacerbation. It's important to recognise the symptoms of a flare-up so you know what to do. Discuss this plan with your healthcare professional:

### Do I feel worse than usual?

#### Symptoms may include:

- Increased breathlessness
- Increased coughing

### I must remember...

- to contact my practice nurse, GP or my community respiratory team
- if my symptoms are severe and it's an emergency, I must call 999.

### My flare-up action plan

If I feel worse than usual, I will...

I will contact...

# My goals

It can help to think about what is important to you – a personal goal or to help maintain your health – and then plan how to achieve it.

### What do you want to do?

- to be able to go for a walk around your local park?
- to visit someone in your family who lives far away?
- to find out about a power of attorney or talk to someone about planning for the future?

Tip: stay motivated by thinking why you want to do this.

### **Reward yourself**

When you set yourself goals, think about how you will reward yourself when you achieve them. Then think about setting yourself another goal.

**If you don't achieve your goal, that's OK.** Take some time to think about why you didn't achieve it. Think about making changes to your goal to make it more achievable. For example, going for a shorter walk.

### My goals

Write down your goals and why they're important to you. Think about what you want to achieve, why you want to achieve it, and how you're going to achieve it.

### Did you find this information useful?

Each year over 400,000 people rely on our expert advice to make key decisions about their lung health. And today, you were one of them.

If you found this information useful and would like to help others access our expert advice, please consider making a kind gift. To donate: call **0300 222 5800**, visit **asthmaandlung.org.uk/leaflets** or scan the QR code. Thank you.

Scan the QR code with your phone's camera to donate today.



## Call our helpline on **0300 222 5800**

#### We are here to help:

- answer your questions, whether that's about coping with symptoms, your rights or finding equipment
- provide clear and trustworthy information about breathing problems and living with a lung condition
- you to get in touch with your local support group

Our friendly team are here Monday to Friday 9am to 5pm. Calling will cost the same as a local call. It's usually free, depending on your call package, even from a mobile.

Or visit **AsthmaAndLung.org.uk** to find support information or join our web community.

- Get support and information
- Sign up to our newsletter
- Find your local support group
- join our web community

# ASTHMA+ LUNG UK

#### Helpline: 0300 222 5800

AsthmaAndLung.org.uk

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