

[www.actionpf.org](http://www.actionpf.org)

# Pulmonary fibrosis journal

Name:

Phone number:



Interstitial Lung Disease  
Interdisciplinary Network



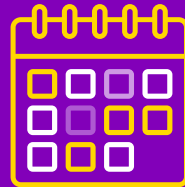
Action for  
Pulmonary  
Fibrosis

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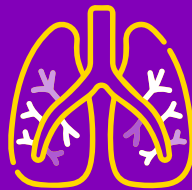
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## Here to help...

The APF support line is here for anyone affected by pulmonary fibrosis, whether you have the condition yourself or know someone who does. The support line is answered by a team of staff and volunteers with a range of skills and experiences. We're here to offer information, signposting, or a friendly ear when you need one.

You can also find information on our website. We have a growing library of resources on different aspects of life with pulmonary fibrosis, from carer's assessments to cough management.

Contact our support team:  
[support@actionpf.org](mailto:support@actionpf.org)



Support line:  
**01223 785725**

Follow us on socials:



# My medical details

Pulmonary fibrosis diagnosis:

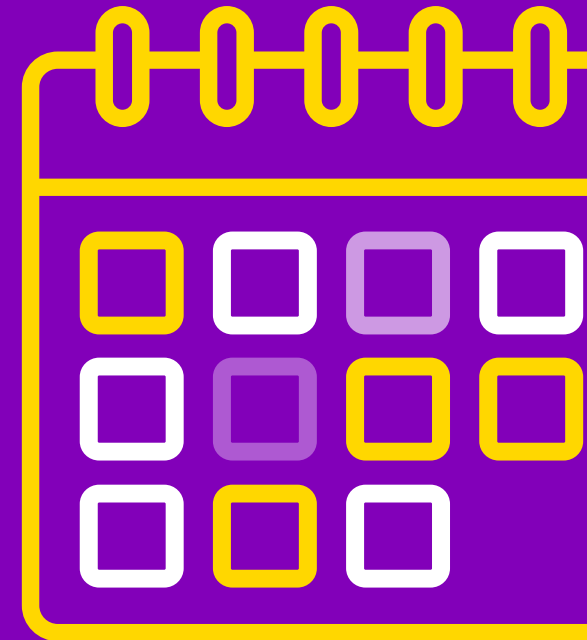
Date of diagnosis:

Medical conditions, allergies and medications:

| Medical condition | Medication |
|-------------------|------------|
|                   |            |

Allergies

# Pulmonary fibrosis journal: managing my appointments



# My healthcare team

The healthcare professionals in a team will vary. Your medical team might not have all the professionals listed below.

## My local hospital or ILD centre:

Name:

Contact:

**ILD consultant:** A senior doctor who will lead your medical treatment. They work alongside other doctors and health professionals to help you make decisions about your treatment.

Name:

Contact:

**ILD nurse:** A specialist nurse who will support your ongoing care. They can advise on all aspects of pulmonary fibrosis including symptom management and information on your condition.

Name:

Contact:

**ILD pharmacist:** A specialist pharmacist who will advise on medication.

Name:

Contact:

**Physiotherapist:** They will support symptom management including breathlessness and getting around, and advise on all aspects of physical well-being.

Name:

Contact:

**Occupational therapist:** They will support you to manage everyday activities alongside your symptoms.

Name:

Contact:

**Community respiratory team:** A team of different professions who deliver care at your home or local facilities.

Name:

Contact:

**Palliative care nurse:** A specialist nurse who will support you to have the best quality of life at any point after your diagnosis.

Name:

Contact:

## Oxygen supplier:

Name:

Contact:

## Others:

Name:

Contact:

Name:

Contact:

Name:

Contact:

Name:

Contact:

# Healthcare checklist

## As part of my diagnosis I had:

- An explanation of pulmonary fibrosis including the possible type

## I have discussed the following with a healthcare professional:

### Treatment

- If antifibrotic medication is suitable for me
- If a lung transplant is suitable for me
- If I would benefit from oxygen therapy (this involves breathing air that has more oxygen than normal air)
- Opportunities to get involved in research

### Living well

- Diet and exercise
- Pulmonary rehabilitation
- Mental health support
- Stop smoking advice
- Vaccinations
- Local support groups

My local group is: \_\_\_\_\_

### Symptom management

- Managing cough
- Managing breathlessness
- How to manage worsening symptoms
- Managing tiredness

### Ongoing care

- Where to find more information or who to ask questions
- Further pulmonary (lung) function tests
- A referral to Action for Pulmonary Fibrosis
- How my condition will be monitored

# Questions you may want to ask

## Diagnosis and treatment:

- Do you know why I have developed pulmonary fibrosis?
- Do you know how advanced my fibrosis is?
- Is my fibrosis progressive?
- What treatments can I have?
- What's the aim of the treatment?
- If I choose not to have treatment, what would happen?
- Can I be treated privately or by a different hospital?
- Are there any research studies I can take part in?

## Living with pulmonary fibrosis:

- Where can I get more information about pulmonary fibrosis?
- Is there any support available for me and my family?
- What can I do to help myself ?
- Is there a patient support group nearby you could refer me to?
- Is there a healthcare professional who I can phone from home if I am worried about anything?
- Where can I learn more about managing my symptoms?

# Appointment diary

|                          |   |
|--------------------------|---|
| Date/time:               | 1 |
| Healthcare professional: |   |
| Reason for appointment:  |   |
| Questions to ask:        |   |
| Discussion/outcome:      |   |

|                          |   |
|--------------------------|---|
| Date/time:               | 2 |
| Healthcare professional: |   |
| Reason for appointment:  |   |
| Questions to ask:        |   |
| Discussion/outcome:      |   |

|                          |   |
|--------------------------|---|
| Date/time:               | 3 |
| Healthcare professional: |   |
| Reason for appointment:  |   |
| Questions to ask:        |   |
| Discussion/outcome:      |   |

|                          |   |
|--------------------------|---|
| Date/time:               | 4 |
| Healthcare professional: |   |
| Reason for appointment:  |   |
| Questions to ask:        |   |
| Discussion/outcome:      |   |

|                          |   |
|--------------------------|---|
| Date/time:               | 5 |
| Healthcare professional: |   |
| Reason for appointment:  |   |
| Questions to ask:        |   |
| Discussion/outcome:      |   |

|                          |   |
|--------------------------|---|
| Date/time:               | 6 |
| Healthcare professional: |   |
| Reason for appointment:  |   |
| Questions to ask:        |   |
| Discussion/outcome:      |   |

Date/time:

7

Healthcare professional:

Reason for appointment:

Questions to ask:

Discussion/outcome:

Date/time:

8

Healthcare professional:

Reason for appointment:

Questions to ask:

Discussion/outcome:

Date/time:

9

Healthcare professional:

Reason for appointment:

Questions to ask:

Discussion/outcome:

Date/time:

10

Healthcare professional:

Reason for appointment:

Questions to ask:

Discussion/outcome:

Date/time:

11

Healthcare professional:

Reason for appointment:

Questions to ask:

Discussion/outcome:

Date/time:

12

Healthcare professional:

Reason for appointment:

Questions to ask:

Discussion/outcome:

Date/time:

13

Healthcare professional:

Reason for appointment:

Questions to ask:

Discussion/outcome:

Date/time:

14

Healthcare professional:

Reason for appointment:

Questions to ask:

Discussion/outcome:

Date/time:

15

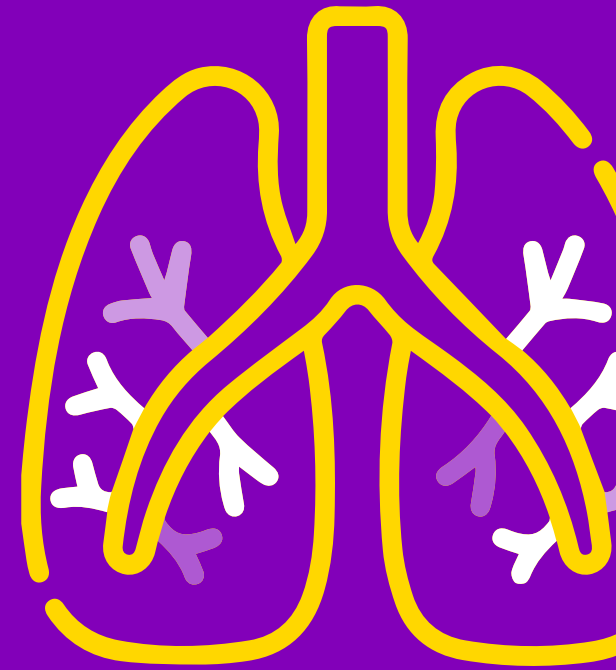
Healthcare professional:

Reason for appointment:

Questions to ask:

Discussion/outcome:

# Pulmonary fibrosis journal: managing my symptoms



# Symptom diary

Recording your symptoms can sometimes be helpful. For example, if you experience a new symptom and want to remember to talk to your ILD team about it. Recording all your symptoms can cause you unnecessary worry or anxiety, so only use this diary if it is helpful for you.

| Symptom description: | Date and time: | Was there a cause?<br>What helped? |
|----------------------|----------------|------------------------------------|
|                      |                |                                    |
|                      |                |                                    |
|                      |                |                                    |
|                      |                |                                    |
|                      |                |                                    |
|                      |                |                                    |

| Symptom description: | Date and time: | Was there a cause?<br>What helped? |
|----------------------|----------------|------------------------------------|
|                      |                |                                    |
|                      |                |                                    |
|                      |                |                                    |
|                      |                |                                    |
|                      |                |                                    |
|                      |                |                                    |
|                      |                |                                    |

# Breathlessness scale

Using a scale can be helpful when describing shortness of breath (breathlessness). It can make it easier to see how your symptoms change over time or with different activities.

This is the Modified Medical Research Council (mMrc) Dyspnoea (shortness of breath) Scale. Select the description that best describes you at this time. Record the grade and date on the opposite page.

**Grade:**                      **Description of Breathlessness:**

---

**Grade 0**

I only get breathless with strenuous exercise.

**Grade 1**

I get short of breath when hurrying on level ground or walking up a slight hill.

**Grade 2**

On level ground, I walk slower than people of the same age because of breathlessness, or I have to stop for breath when walking at my own pace on the level.

**Grade 3**

I stop for breath after walking about 100 yards or after a few minutes on level ground.

**Grade 4**

I am too breathless to leave the house or I am breathless when dressing.

'The modified MRC was developed by D A Mahler. DOI: 10.1378/chest.93.3.580'

Date:

Grade:

Date:

Grade:

Date:

Grade:

Date:

Grade:

Date:

Grade:

Date:

Grade:

Date:

Grade:

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Grade:

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Date:

Grade:

# My oxygen prescription

Some people who have pulmonary fibrosis might benefit from oxygen therapy. This involves breathing air that has more oxygen than normal air. If you have a prescription for oxygen, you can use this page to record the details of how to use it. This might change over time so you can cross out the old details and fill in a new line below.

(Circle correct information as needed)

My oxygen is: ambulatory\*/at rest/both/other      Date: \_\_\_\_\_

My oxygen is: ambulatory\*/at rest/both/other      Date: \_\_\_\_\_

My oxygen is: ambulatory\*/at rest/both/other      Date: \_\_\_\_\_

My oxygen is: ambulatory\*/at rest/both/other      Date: \_\_\_\_\_

My oxygen is: ambulatory\*/at rest/both/other      Date: \_\_\_\_\_

My oxygen is: ambulatory\*/at rest/both/other      Date: \_\_\_\_\_

At rest/ambulation\* I need: \_\_\_\_\_ L/m of oxygen      Date: \_\_\_\_\_

At rest/ambulation\* I need: \_\_\_\_\_ L/m of oxygen      Date: \_\_\_\_\_

At rest/ambulation\* I need: \_\_\_\_\_ L/m of oxygen      Date: \_\_\_\_\_

At rest/ambulation\* I need: \_\_\_\_\_ L/m of oxygen      Date: \_\_\_\_\_

At rest/ambulation\* I need: \_\_\_\_\_ L/m of oxygen      Date: \_\_\_\_\_

At rest/ambulation\* I need: \_\_\_\_\_ L/m of oxygen      Date: \_\_\_\_\_

Target oxygen saturations: \_\_\_\_\_      Date: \_\_\_\_\_

Target oxygen saturations: \_\_\_\_\_      Date: \_\_\_\_\_

Target oxygen saturations: \_\_\_\_\_      Date: \_\_\_\_\_

Target oxygen saturations: \_\_\_\_\_      Date: \_\_\_\_\_

Target oxygen saturations: \_\_\_\_\_      Date: \_\_\_\_\_

Target oxygen saturations: \_\_\_\_\_      Date: \_\_\_\_\_

\*Ambulation: moving around

# Worsening symptoms

Your pulmonary fibrosis symptoms might sometimes get worse. For most people, it's normal to have slight variations in symptoms from day to day. Some changes need looking into. There might be a cause of the worsening symptoms that needs treating. You should make sure to tell your healthcare team if you notice:

- Your breathlessness has worsened, particularly at rest.
- Your cough is worse and you cough up more mucus (phlegm) than usual. Or, the mucus is a different colour. It might be yellow or green.
- You have a temperature, feel more tired than usual or feel unwell.

**If I think my symptoms are worsening, I should:**

(Fill this out with your medical team)

If you are having difficulty breathing or need emergency help, call 999.



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

**Here to help...**

Email our support team:  
[support@actionpf.org](mailto:support@actionpf.org)



Support line:  
**01223 785725**

If you need this information in a different format such as large print, easy read or another language, please contact us.

**General enquiries:**

01733 839642  
[info@actionpf.org](mailto:info@actionpf.org)

[www.actionpf.org](http://www.actionpf.org)

**Follow us on socials:**



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Pulmonary  
Fibrosis**

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