



## About me

This page was updated by .....

Date (dd/mm/yy) .....

Name .....

has been diagnosed with .....

.....

.....

My home address .....

.....

My date of birth is (dd/mm/yy) .....

My NHS number is .....

My hospital number is .....

The hospital I go to is .....

.....

My contact at the hospital is .....

Telephone .....

I have these allergies .....

I have these other conditions .....

.....

.....

My emergency contact is (this may be a family member, friend or carer)

.....

.....

Their telephone .....

Other important information .....

.....

.....

.....

.....

## My key contacts

Add anyone you think is useful. You could include your specialist nurse, community nurse or GP, a friend or family member to call on for help, an out-of-hours emergency contact, your lasting power of attorney, your support group information, your oxygen provider and others.



**Key contact name** .....

**Relationship/role** .....

**Telephone** .....

**Email** .....

**Notes** .....

.....

.....

**Key contact name** .....

**Relationship/role** .....

**Telephone** .....

**Email** .....

**Notes** .....

.....

.....

**Key contact name** .....

**Relationship/role** .....

**Telephone** .....

**Email** .....

**Notes** .....

.....

.....





## My checklist

Your specialist team can help you feel better and improve your quality of life. Discuss these options with your health care professionals to see what best meets your needs:

- stopping smoking**
- having a pneumonia jab and a yearly flu jab**
- getting information and support from a specialist nurse**
- information about support groups**
- getting access to pulmonary rehabilitation, a type of exercise programme**
- medication to help my symptoms, and any tips and advice**
- getting access to oxygen therapy**
- medication to slow the scarring in my lungs**
- regular follow-up appointments**
- research programmes I'm interested in**
- having a lung transplant**

# My treatment

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



Name of medication or treatment .....

Date started (dd/mm/yy) .....

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

.....

.....

.....

Date ended (dd/mm/yy) .....

Name of medication or treatment .....

Date started (dd/mm/yy) .....

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

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.....

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Date ended (dd/mm/yy) .....

Name of medication or treatment .....

Date started (dd/mm/yy) .....

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

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.....

.....

Date ended (dd/mm/yy) .....



## My flare-up plan

Sometimes, when your health has been stable, your symptoms may flare up. This is also called an acute exacerbation. It's important to recognise the symptoms of a flare-up and to know what to do. Discuss this plan with your health care 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 to call 999

### My action plan

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

.....

.....

.....

.....

I will contact... ..

.....

.....

.....

.....

# My appointments

Keep track of all your appointments with your GP, nurse, specialists and others. You could also record home visits and important phone calls.



**Appointment date (dd/mm/yy)** .....

**Meeting with** .....

**Test(s) I had** .....

**What they told me/notes** .....

**Questions I want to ask** .....

# My feelings

It can help to write down how you feel so you can identify the areas where you need further help and support.



How do I feel today < 0 1 2 3 4 5 6 7 8 9 10 >  
*Not great* *Really good*

Today I'm worried about .....

Date (dd/mm/yy) .....

My concerns are:

- practical
- emotional
- lifestyle
- spiritual or religious
- financial
- family or relationships

Who can I talk about this .....

How do I feel today < 0 1 2 3 4 5 6 7 8 9 10 >  
*Not great* *Really good*

Today I'm worried about .....

Date (dd/mm/yy) .....

My concerns are:

- practical
- emotional
- lifestyle
- spiritual or religious
- financial
- family or relationships

Who can I talk about this .....



## 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 to plan for the future?

**Tip:** Stay motivated by thinking **why** you want to do this. When you succeed, give yourself a big pat on the back and think about another goal.

**What is important to you?** .....

.....  
.....  
.....  
.....

**My goal is** .....

.....  
.....  
.....

**I would like to do this by (date)** .....

**Who can help me?** .....

.....  
.....

**Steps I will take to make this happen**

**Step 1** .....

.....  
.....

**By** .....

**Step 2** .....

.....  
.....

**By** .....

**Step 3** .....

.....  
.....

**By** .....



## Information for my health care professional

For specialists, GP, nurse or other health care professionals in a clinic or at my home.

I am using a pulmonary fibrosis organiser developed by the British Lung Foundation to manage my condition and feel more in control.

I'd like to share my organiser with you as one of my health care team. It will help us talk about what is important to me – what I want to achieve, how I feel and my questions.

I'm grateful for your support. It's suggested we talk about the personal organiser each time we meet.

**This personal organiser does not replace or duplicate medical notes.**

**The BLF developed this organiser with health care professionals, patients and carers. It was piloted at two ILD specialist hospitals in the UK. The clinical content was developed using NHS Information Standard processes.**

**You can find further pulmonary fibrosis resources at [blf.org.uk/pf](http://blf.org.uk/pf)**

Get in touch to find support near you.

**Helpline: 03000 030 555**

Monday to Friday, 9am-5pm

Ringling our helpline never costs more than a local call and is usually free, even from a mobile.

**[helpline@blf.org.uk](mailto:helpline@blf.org.uk)**

**[blf.org.uk](http://blf.org.uk)**

### British Lung Foundation

73-75 Goswell Road, London EC1V 7ER

Registered charity in England and Wales (326730), Scotland (038415) and the Isle of Man (1177).

Code: PFO Version: 2

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We value feedback on our information. To let us know your views, and for the most up to date version of this information and references, call the helpline or visit [blf.org.uk](http://blf.org.uk)



The Information Standard Certified Member