



About me

This page was updated by

Date

Name

has been diagnosed with

My home address

My date of birth is

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 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

Meeting with

.....

Tests I had

.....

.....

.....

.....

My test results were

.....

.....

.....

.....

.....

What they told me/notes

.....

.....

.....

.....

.....

Questions I want to ask

.....

.....

.....

.....

.....

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, any side effects)

.....

.....

.....

Date ended

Name of medication or treatment

Date started

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

.....

.....

.....

Date ended

Name of medication or treatment

Date started

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

.....

.....

.....

Date ended



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. Let's talk about the personal organiser each time we meet.

This personal organiser does not replace or duplicate medical notes.

The British Lung Foundation developed this organiser with health care professionals, patients and carers. It was piloted at two ILD specialist hospitals in the UK.

You can find further pulmonary fibrosis resources at 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

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: 3

Last review: July 2019 Next review: July 2022

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

PF Personal Organiser



blf.org.uk/pf

My diagnosis

☐ I was given my diagnosis by a multidisciplinary team.

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

What I've been told about my diagnosis

I was told by

Date _____

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 health care professionals regularly to see what best meets your current and future needs:

- ☐ **stopping smoking**
- ☐ **having a pneumonia jab and a yearly flu jab**
- ☐ **getting information and support from a specialist nurse**
- ☐ **information about support groups**
- ☐ **being referred to pulmonary rehabilitation (PR), a structured exercise and educational programme**
- ☐ **medication to help my symptoms, and being referred to support services (such as palliative care services) to help with and give advice about controlling 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, 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 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