

# Pulmonary fibrosis

## patient passport



### Get the best care

There are many different types of pulmonary fibrosis. Most of them cause scarring or inflammation in your lungs.

The treatment you may need can vary a lot. It's important you understand how your condition is managed, how to manage your symptoms and get specialist help. Discuss this checklist with your doctor or nurse to make sure you get the best care.

### Talk to your doctor or nurse if you can't say yes to every step:



1 My diagnosis was made by a specialist multidisciplinary team (MDT).

2 I have access to a specialist nurse for information and support. I know where to find more help and I have information about local patient support groups.

3 My family, carers and I can access specialist services to help with and advise about controlling my symptoms and psychological care.

You and your family may benefit from palliative care at any stage after your diagnosis.

4 If I need it, I have medication to help with my symptoms. I know what to do if my condition gets worse or if my symptoms flare up (an exacerbation). At some times, the best treatment may be to monitor your condition.

5 If I have IPF, and am eligible, I have been offered anti-fibrotic medication to slow down the scarring in my lungs.

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- 6 I know it's important for me to keep active and I've been offered a referral to pulmonary rehabilitation (PR).
- 7 I have lung function tests before, or at, my clinical reviews.
- 8 My oxygen levels are assessed at my clinic appointments. If appropriate, I have been referred for an oxygen assessment and given oxygen therapy.
- 9 I have discussed with my consultant if a lung transplant is suitable for me.
- 10 I know to get a free flu jab each year - available from October from my GP, nurse or pharmacist. I have also had a one-off pneumonia jab.
- 11 I have been given information about how my diet can help my condition.
- 12 If I smoke, I am offered support and treatment to stop every time I see my doctor or nurse about my pulmonary fibrosis.
- 13 I see my health care specialist at least twice a year to review my care.

You may want to ask about any clinical trials or new treatments.

## We're here to help.

Our friendly **helpline team** are here to answer your questions.

Visit **[blf.org.uk](https://blf.org.uk)** for advice and information about pulmonary fibrosis.

Join one of our **support groups** across the UK for information and understanding from people living with a lung condition.

Helpline: **03000 030 555**

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

**[blf.org.uk/pulmonary-fibrosis](https://blf.org.uk/pulmonary-fibrosis)**



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