

A guide to discussing pulmonary fibrosis with your healthcare team

If you have recently been diagnosed with pulmonary fibrosis, you may be looking for ways to talk to your healthcare team about it. There are treatments that can help. Your healthcare team can give you information about these treatments, symptom management and much more.

Being prepared for your appointments with a few pre-determined questions can be helpful. Consider asking your doctor or nurse some of the example questions below. Prioritizing 2 or 3 questions that are important to you may help ensure that they get answered first.

Choose your questions from the list below

Symptoms

- Who can I talk to about practical issues if I can't manage my symptoms?
- What can be done to manage or treat my symptoms?
- How long are my symptoms likely to last?
- Why would my symptoms be getting worse?
- What changes do I need to watch for in terms of my breathing ability?
- When am I at the biggest risk of developing worsening lung problems?
- How will my symptoms be monitored?
- Is it normal to be feeling the way I do?
- I have been feeling really down. Is this normal?

Treatment

- What can be done, or what treatments are available?
- What treatments can help?
- Can you tell me about the potential benefits?
- What are the side effects of treatment?
- When is the right time to start treatment?

Emotional well-being

- Who can I speak to about how I am feeling?
- Are there any support groups that I could get in touch with?
- Will I be able to go on holiday?

Lifestyle

- Do I need to change what I eat?
- What exercise can I do?
- Are there any activities that I need to avoid?
- Are there any gadgets that might help me around the house or when I'm out?

Work life

- Will I be able to carry on working?
- Am I entitled to any support at work?
- How can I explain my pulmonary fibrosis to my employer?
- Can I ask for some changes to my job?
- If I have to stop working, will there be any financial support for me?

Looking to the future

- What's going to happen next?
- How is this going to affect me over the next year?
- Can I have children?
- Will my children get pulmonary fibrosis?

Remember that it is okay to ask your doctor to repeat what they said or ask them to explain it in a different way. You can also ask the same question more than once and ask them to give you some time to take notes, so you don't have to remember it all. The most important thing is that you come out of your appointment feeling like you understand the information you have been given. It's also beneficial to bring a family member or caregiver to the appointment to help you with questions and taking notes. That way, there will also be a mutual understanding at home once the appointment is over.

Notes:

