

Telling people you have pulmonary fibrosis

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Interstitial Lung Disease
Interdisciplinary Network



Action for
Pulmonary
Fibrosis

There's no right or wrong way to tell your family and friends you have pulmonary fibrosis. You don't have to tell anyone if you don't want to, but talking about your diagnosis can help you feel more supported. If you find it difficult to tell people, these ideas might make it a little easier.

When do I tell people?

Tell people when it feels right for you and when you are emotionally ready to talk about your diagnosis. Some people want to learn more about pulmonary fibrosis and process their diagnosis on their own before telling others.

How do I tell people?

How you choose to tell people is very individual. You might want to try:

- Talking to a group of family and friends at the same time.

- Having one-to-one conversations with individual people.
- Telling one person who acts as a 'messenger' to tell others.
- Bringing family and friends to medical appointments. Healthcare professionals can help to explain your diagnosis.
- Giving your family and friends something to read so you don't have to explain everything. We have online and printed resources that help people understand what pulmonary fibrosis is.



"The biggest thing to get over is the disbelief of 'Really, no cure? Are you sure?' that kind of thing. To all that asked, I try to explain in layman's terms what this is and what it means long term. My best approach is to tell the truth as you understand it. No point in leaving any detail out."

Jeff Taylor-Jackson

Where do I have the conversation?

Choose a place where you feel comfortable and able to talk openly. This might be at home over a coffee or whilst out for a walk in a quiet area.

What should I say?

- If you're unsure where to start, you could use a simple phrase to describe pulmonary fibrosis overall. This could be something like: 'I have a condition called pulmonary fibrosis. This means my lungs have scar tissue, which stops them from working properly. The amount of scar tissue might increase over time.'
- Think about the most important things you want them to know. Is it how pulmonary fibrosis affects your daily life? Is it that you are worried about the impact of your diagnosis on your work or family?
- Consider your own needs. It can be tempting to downplay your diagnosis or put a positive spin on it, but tell people how you feel so they can support you.
- Let people know how they can help and support you. Whether that's practical help with things like shopping, or having someone to talk to when needed.
- You can invite them to support groups to learn more about pulmonary fibrosis and feel supported by a community. There is a specific support group for carers, family members and friends, but they can also attend the regional support groups that are open to everyone.

How should I expect the conversation to go?

- Telling people about your diagnosis might make you feel very emotional, and this is okay. Let yourself feel your emotions and let others know how you feel.
- Don't worry too much about silences. Some people need time to take in the information before responding, especially in an emotional situation.
- Consider their potential reactions and how you might deal with this. For example, some people might be very emotional, and others may not say much.
- When you tell people you have pulmonary fibrosis, some people might do their own research to find treatments or cures. Whilst they are well-meaning, there is a lot of information out there that is not accurate. You should always ask your healthcare team before trying any suggestions. If someone has suggested you try something you don't want to try, you can tell them that you need to discuss this with your healthcare team first, as not everything is suitable for everyone.

Explaining pulmonary fibrosis to children

Talking about pulmonary fibrosis can be difficult but it's usually best to be honest about your diagnosis with the children in your life. They might be able to tell that something has changed, and this uncertainty can lead to them making assumptions and worrying.

Give reassurance

- It can be helpful to reassure children that this is not usually something that happens in childhood, and only a very small number of adults get it.
- You can also reassure them they will still be safe and looked after, whatever happens to you.



Where and when?

- Have a conversation when they can think about what you've said and ask questions. You might want to avoid telling them just before they go to school or before bedtime.
- Choose a place where they feel safe and comfortable.

"When I found out I had pulmonary fibrosis, I told my children and we dealt with it using a lot of humour. They now tell me it took some of the anguish out of the situation. It's not what I'd recommend to everyone, but it got us through."

Andy Bright

What to say

- What you say might depend on their age and understanding. If you're telling multiple children with significant age gaps, it might be helpful to tell them separately. This way you can adjust what you say to their level of understanding.
- For many children, you can explain pulmonary fibrosis by saying that your lungs are not working as well as most people's, making breathing harder for you. You might want to describe how this affects your daily life so they understand that you might need to do some things differently.
- Be honest and use straightforward language so they don't misinterpret what you're saying.
- You don't have to tell them everything in one conversation.
- It's okay to say 'I don't know' to something they ask you.

Get support

- Involve another adult that the children are close to. If you are their grandparent, you could talk with the children and their parents. This can help to build a support network, so you and the children have someone else to go to with questions or worries.



If you need support telling your family and friends about your diagnosis, call our support line on **01223 785 725** or email supportline@actionpf.org



**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



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.

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