

## WORKING WITH YOUR DOCTOR

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When facing a rare and serious lung disease such as idiopathic pulmonary fibrosis (IPF), it's important to get the best possible care. However, primary care doctors may have limited experience with IPF. Plus, because IPF is so rare, many experienced pulmonologists may have had limited opportunity to treat many IPF patients themselves. This is why you may want to try to find a pulmonologist who has experience caring for patients with IPF.

### Tips for Getting the Most from Your Doctor Visit

The suggestions below are based on publications by the Agency of Healthcare Research and Quality and The Joint Commission. Note that these are general guidelines for any patient and are not specific to people with IPF.

- **Don't be afraid to ask questions.** If you do not understand something about your disease, or instructions you have just been given, don't hesitate to ask your doctor or other healthcare provider to explain it further. Asking questions and sharing information may help improve the quality of the care you get
- **Come to your visits prepared.** You may find it helpful to write down questions in between appointments, and bring the list of questions with you. Since time with your doctor is always limited, this will help you make the most of it; also, write down a list of any medicines you are currently taking
- **Bring a notepad.** You may find that at some of your appointments, you'll be given what seems like an overwhelming amount of information. It's OK for you to take notes to help you follow important instructions and information in the future
- **Bring someone with you.** A friend, family member, or other caregiver may be able to help by taking notes, scheduling appointments, and by giving the doctor another point of view on how you are living with your

disease or what effect a treatment may be having

- **Follow up with your doctor.** If you need further explanation about your condition or instructions for care once you get home, call your doctor. Also, ask about the results of any tests your doctor may have performed and any next steps you need to take. Always call your doctor if your symptoms get worse

## Other Things You Can Do



**Reach out to the IPF community.** You may find it useful to contact IPF advocacy and support groups to get advice and tips that can help you manage your symptoms. You may also get answers or advice that you'll want to run by your doctor. Sometimes, it's also nice just to connect with other people who truly understand what you're going through. (Connect with other people living with IPF. Learn about [online support groups](#))

- **Don't stop learning.** Knowing as much as you can about IPF and how it will affect you will let you:

- Set realistic goals
  - Make meaningful choices
  - Remain in control of your care longer
  - Enjoy daily activities for as long as possible
- Always be sure to go to reliable, respected sources for your healthcare information.
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