

## Stage 1: Recently Diagnosed with Idiopathic Pulmonary Fibrosis (IPF)

There is no formal staging system for IPF. However, thinking of IPF in four stages can help people with IPF and their caregivers prioritize their needs and keep them from feeling overwhelmed. Although education regarding a variety of topics can occur at any time, the stages may help patients and their caregiver focus on what is needed and what to expect as time goes by.



### The Four Stages of IPF

- Stage 1: Recently diagnosed
- Stage 2: Needing oxygen with activity, but not at rest
- Stage 3: Needing oxygen 24 hours a day, with activity, at rest and during sleep
- Stage 4: Advanced oxygen needs (needing high-flow oxygen or when a lightweight, portable delivery system is unable to meet a patient's needs).

### Stage 1: Recently diagnosed

#### What should I focus on when I am recently diagnosed?

When you are diagnosed with IPF you may want to:

- Partner with your pulmonologist to develop and individualize your action plan.
- Learn about IPF, including the symptoms, treatment and prognosis.
- Live a full life with IPF through:
  - Regular exercise. Stay active. Physical exercise is the most important thing you can do for yourself.
  - Healthy eating
  - Rest
  - Support from others
- Consider joining a support group in your area.
- If you smoke, work with your doctor on quitting smoking.
- Think about what you can do to avoid infections.
- Begin thinking and talking about advance directives.

- Focus on today — on what you can do, not what you can't.
- Live life one day at a time.
- Consider purchasing a finger pulse oximeter and “check in” with the oximeter occasionally while performing activities of differing energy demands, and keep a log. Tell your doctor if readings are ever below 90 percent.

### How can the caregiver help?

- Empower yourself by learning about IPF with your partner.
- Attend health care appointments to be a second set of ears.
- Discuss and write down questions to ask the health care provider.
- Help keep a record of care.
- Help keep track of medications.
- Encourage the person with IPF to live a full life, including regular exercise, healthy eating, rest and support from others.
- Keep a good supply of waterless soap around the house and in a to-go bag.
- Consider attending a support group, either alone or with your patient/loved one.
- Build your own support network consisting of family, friends and/or other caregivers.
- Remember to take care of yourself. Having a loved one with a serious illness can lead people to forget about themselves and their own health. You will not be a good caregiver if you are physically ill or emotionally unwell. Spend some time doing things you enjoy to avoid getting burned out.

### How might a caregiver be affected?

You may experience a range of emotions when your loved one is diagnosed; these could include denial, fear, stress, anger/frustration, grief or depression. It is important to know that your loved one may not experience the same emotions as you, or he or she may not experience emotions at the same time.

- Denial: It may be hard to believe or accept that your loved one has IPF. Experiencing denial for a short period of time is natural; however, longer-term denial is unhealthy and may affect your loved one and delay the initiation of appropriate therapy.
- Fear: Fear of the unknown is common. Not knowing how IPF will behave over time is unsettling. Try to focus on the here and now, rather than the what-ifs.
- Stress: Not knowing how to help your loved one with IPF can lead to stress. Try to find activities to relieve your stress. Planning for the future can help alleviate stress.
- Anger/frustration: It is normal to feel anger and/or frustration at IPF when a loved one is diagnosed. Try to work through it.
- Grief/depression: You have not lost your loved one. Your loved one and you have a lot of living to do. Focus on today and on what you can do, not what you can't.

### What to expect from the person with IPF in this stage

- The person with IPF may be entirely asymptomatic; however, it would not be uncommon for them to have shortness of breath when exerting, dry cough and/or fatigue.

- Shortness of breath may only be present with extreme exertion (e.g., climbing a hill). Remember, even people without IPF are at least a little short of breath going up two flights of stairs.
- Cough can be frequent and bothersome. It may only occur when the person with IPF talks for long periods of time or when they are exerting.
- Fatigue is common and challenging to treat. Eating well, exercising and getting plenty of high quality sleep can help.
- The person with IPF who is just diagnosed may experience an array of emotions. They may be afraid or angry, anxious or short-tempered.
- Many people with IPF in Stage I want to know more about the disease. We discourage online searching at random sites, because much of the information is outdated or inaccurate.

### Questions to ask your health care provider

- What treatments are available to me now?
- How will those treatments affect my quality of life?
- What should my caregiver and I expect as my disease progresses?
- Are there any support groups available for me to connect with fellow IPF patients?
- Are there good websites that provide helpful, reliable information?
- Do I need any vaccines?
- Do I have or need treatment for acid reflux?
- Do I have pulmonary hypertension? Should I be tested?
- Do I have obstructive sleep apnea? Should I be tested?

Visit our website for more information about support groups, clinical trials and lifestyle information.

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