

Stage 2: Needing Oxygen with activity, but not at rest with 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 2: Needing oxygen with activity, but not at rest

What should I focus on when needing oxygen with activity, but not at rest?

- Work with your health care provider. The health care provider will write a prescription for oxygen based on your oxygen saturations with rest and activity. A durable medical equipment (DME) company will provide the oxygen.
- Learn about the medical equipment. This includes the stationary/in-home and portable oxygen systems that are available.
- Use a pulse oximeter to check your oxygen saturations when you are active or exercising to make sure you are getting the right flow of oxygen to maintain your saturation equal to or greater than 89 percent.
- Ask about the medications that may be used for IPF. Learn the dose and time the medicine is taken, how it may be helpful and what side effects to watch for.
- Breathing retraining may be helpful with the shortness of breath that can occur with exercise.

Learn and practice the breathing techniques.

- Remember to continue living a full life with IPF activities.
 - Regular exercise is important, and oxygen will help you feel better while you exercise.
- Think about whether lung transplantation is an option for you personally, and share this information with your pulmonologist.

How Can the Caregiver Help?

- Continue to be a second set of ears, with the health care provider, but now with the durable medical equipment (DME) company also. This is a new company you will both need to work with.
- Continue to discuss and write down questions.
- Learn the ins and outs of the new medical equipment. Examples include: oxygen systems, portable oxygen system and pulse oximetry
- Encourage the person with IPF to live a full life, including regular exercise, healthy eating, rest and support from others.
- Read the book Adventures of an Oxy-Phile by Dr. Thomas Petty.
- Remember to take care of yourself.

What to Expect From the Person with IPF in this Stage

- The person with IPF in Stage II is short of breath with exertion or activity.
- 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 not uncommon at this stage and can be challenging to treat. Eating well, exercising and getting plenty of high quality sleep can help.
- Being prescribed oxygen for use during the day is perceived by many people with IPF as a major step in the wrong direction. But, oxygen is not a death sentence! Even so, some people with IPF feel self-conscious using their oxygen in public. This is natural and usually short-lived.

Questions to Ask Your Health Care Provider

- Does staying active actually extend my life or does it just improve my quality of life?
- What resources are available to help me be active with oxygen? Can I travel with oxygen?
- Do I have the freedom to adjust flow rates based on how I am feeling, or am I bound to the prescribed flow rate?
- Do I need to be extra careful when exercising when using oxygen, or is it based on what I can

tolerate?

- Do you recommend formal pulmonary rehab and/or self-initiated physical activity?
- Will you monitor my oxygen needs at clinic visits? If so, how?
- Are my vaccinations up to date?
- Is there a transtracheal oxygen program nearby? Am I a candidate for the procedure?

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