

## Stage 3: Needing oxygen 24 hours a day, with activity, at rest and during sleep 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 3: Needing oxygen 24 hours a day, with activity, at rest and during sleep

#### What should I focus on when I am needing oxygen at rest, activity and sleep?

- Work with your health care provider in the oxygen prescription change and the best oxygen system to meet your needs of using oxygen 24 hours a day.
- Learn about stationary oxygen systems and portable systems.
- Work with the DME company regarding the change in oxygen needs.
- Plan for oxygen use with activities when away from home and traveling. Plan ahead for travel.
- Use your pulse oximeter to monitor your oxygen level. Maintain an oxygen saturation equal to or greater than 89 percent when you rest and are active.
- Your health care provider may discuss palliative care. Ask any questions you have.
- Remember to continue living a full life with IPF activities.
  - Oxygen is now important 24 hours a day and with regular exercise.
  - Regular exercise is still important, and oxygen will help you feel better while you exercise.
- If transplant is an option for you, make sure you are evaluated at a transplant center.

## How can the caregiver help?

- Learn the ins and outs of oxygen systems for use at home, when away from home and when traveling.
- Continue to be a second set of ears, with the durable medical equipment (DME) company as the oxygen needs change.
- Continue to discuss and write down questions.
- Encourage the person with IPF to live a full life, including social interactions, regular exercise, healthy eating, rest and support from others.
- If you haven't yet, get 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 III is short of breath with exertion or activity. Even though they need oxygen at rest, they will not be short of breath at rest.
- 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. Napping is okay and encouraged.
- Being prescribed oxygen for use 24 hours per day is perceived by many people with IPF as yet another major step in the wrong direction. But, even 24/7, oxygen is not a death sentence! Nonetheless, people with IPF may feel afraid, anxious or depressed and be short-tempered with this new stage.

## Questions to Ask Your Health Care Provider

- Do I need to be careful about physical activity?
- Am I a candidate for a lung transplant? If so, what do I do?
- Are my vaccinations up to date?
- Should I enroll or re-enroll in pulmonary rehabilitation?
- Do I have pulmonary hypertension?

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