

Stage 4: Advanced Oxygen Needs 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 4: Advanced oxygen needs (needing high-flow oxygen or when a lightweight, portable delivery system is unable to meet a person with IPFs needs)

What should I focus on when I have advanced oxygen needs?

- Work with your health care provider regarding the oxygen prescription change and the best oxygen system to meet your needs for using oxygen as the liter flow increases 24 hours a day. High liter flow is described as greater than 4 liters. Transtracheal oxygen may be an option.
- Learn about stationary oxygen systems and portable oxygen systems that will meet your oxygen needs at high liter flows.
- Learn how long the portable oxygen system will last at higher liter flows.
- Work with the DME company regarding the change in oxygen needs.
- 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.
- Talk with your health care provider about palliative care.
- Your health care provider may talk with you about the possibility of a lung transplant.
- Remember to stay active and continue living a full life with IPF.

How Can the Caregiver Help?

- Learn the ins and outs of high-flow oxygen system at home, when away from home and when traveling. Calculate how long the portable oxygen system will last when away from home.
- 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.
- Remember to take care of yourself. Consider respite care. Consider palliative care and/or hospice care as indicated.

What to Expect from the Person with IPF in this Stage

- The person with IPF in Stage IV is short of breath with exertion or activity. Even though they need oxygen at rest, they will not usually 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.
- High-flow oxygen cannot be delivered by portable oxygen concentrators, so many people with IPF feel even more constrained. Remember, even high-flow oxygen is not a death sentence! Nonetheless, people with IPF may feel afraid, anxious or depressed and be short-tempered with this new stage. They are at risk for social isolation and mood disturbance.

Questions to Ask Your Health Care Provider

- What is the normal life expectancy at this point?
- What palliative care resources are available?
- What does the end look like?
- Can you guarantee that I will not suffer?

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