

IDIOPATHIC PULMONARY FIBROSIS

Resources for managing your health

Idiopathic Pulmonary Fibrosis (IPF) describes a condition in which there is no known cause (idiopathic) for the development of thickened, stiff and scarred lung tissue (pulmonary fibrosis).

The most common symptom of IPF is shortness of breath, also known as dyspnea, which many patients describe as a feeling of breathlessness.

Other common symptoms include:

- Chronic dry, hacking cough
- Fatigue and weakness
- Discomfort in the chest
- Loss of appetite



Many people think there are no treatments for IPF. In the past, this may have been true, but doctors do have a number of ways to treat IPF.

It is important for you to understand IPF so you can ask your doctor questions based on your individual symptoms. The other side of this card provides recommended questions that you can ask your provider at each stage of IPF.

For more information or questions please call the National Jewish Health nursing line at (303) 398-1355 and select option 4.

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1. Upon Diagnosis

- a. What treatment is available to me and how will it impact my quality of life?
- b. What should my caregiver and I expect as my disease progresses?
- c. Are there any support groups available for me to connect with fellow IPF patients?
- d. Are there good websites that provide helpful, reliable information?

2. When oxygen is needed with activity

- a. Does staying active actually extend my life or does it just improve my quality of life?
- b. What resources are available to help me be active with oxygen? Can I travel with oxygen?
- c. Do I have the freedom to adjust flow rates based on how I am feeling or am I bound to the “prescribed” flow rate?
- d. Do I need to be extra careful when exercising when using oxygen or is it based on what I can tolerate?
- e. Do you recommend formal pulmonary rehab or self-initiated physical activity or both?

3. When oxygen is also needed at rest

- a. At what point should I consider the trans-tracheal procedure for my oxygen needs?
- b. Do I need to be careful about physical activity?
- c. Am I a candidate for a lung transplant? If so, what do I do?

4. When advanced oxygen is needed

- a. What is the normal life expectancy at this point?
- b. What palliative care resources are available?
- c. At what point is it time to say goodbye? How much input should I accept from my loved ones?