

## COMING TO TERMS WITH IPF

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People living with idiopathic pulmonary fibrosis (IPF) must face the distressing fact that their lifespan will almost certainly be shortened. This means that they may need to consider issues and preferences about their end-of-life care sooner than most people normally would.

Being uncertain about the future is a major source of stress for people with IPF and their caregivers. It's normal for patients to fear that their symptoms may not be controlled toward the end and that breathing will become a painful struggle. Like anyone, people with IPF also want their passing to be peaceful. You should talk to your doctor about these concerns because he or she will work with you to try to help you manage breathing difficulties, pain, or discomfort as much as possible.

## Starting the Conversation

Experts recommend that IPF patients and their doctors start the conversation about end-of-life issues before hospice care is required. This is believed to be a good way to avoid an additional source of stress. Your healthcare team can help by addressing end-of-life planning needs, such as:

- Managing your symptoms and the relief of suffering
- Documenting your wishes regarding:
  - Your preferred place of care during your final months
  - What (if any) life-supporting measures you'd like to have taken
  - Where you'd prefer to be at the very end (at home vs a medical facility)

This conversation should be ongoing throughout your care because your needs and wishes may change over time.

As IPF progresses, symptoms make it increasingly difficult for IPF patients to carry out daily activities. But your healthcare team can use a wide variety of approaches to address the unique physical, psychological, and spiritual needs you will have when the time comes.

Since there is no known cure for IPF, as the disease progresses, eventually your only options may be palliative (PAL-ee-uh-tiv) care and/or hospice care. Palliative care can begin anytime a patient needs help with achieving comfort, and it is now recommended as a routine part of the care of people with IPF. Hospice care is typically reserved for patients who are believed to have 6 months or less remaining. ([Learn more about palliative and hospice care.](#))

## **Dr. MaryLuz Fuentes' Story**

See how MaryLuz—a doctor, mother, and patient with IPF—learned to cope with the disease. [Watch other videos about IPF](#)

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