What to Do If You've Just Been Diagnosed

Being diagnosed with a serious disease like idiopathic pulmonary fibrosis (IPF) can turn your life upside down and force you to adjust your life goals. It is normal for people with IPF to experience fear, worry, anxiety, and panic as they anticipate the decline in their ability to function and a loss of independence. Many want to stop taking part in social activities and some may experience a strain on their relationships. It’s important for you to recognize that these are all normal feelings and that you must find ways to cope with them. Your healthcare team should be able to get you the support you need.

The following is a list of some practical tips to give some guidance to someone who has just been diagnosed with IPF:

1. **Learn about IPF progression**
   - Find out all you possibly can about IPF:

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The fact that you are here at this site means that you’ve already begun learning more about IPF. Of course, your primary source for information about IPF should always be your doctor. He or she will give you information about the disease and help treat your IPF with a plan that is customized just for you. Other sources, both online and offline (such as support group meetings), can give you even more information. The more aware you become of IPF and treatment options, the more of a role you can play in your own care.

2. **Find the right pulmonologist:**
   Pulmonologists are experts in lung function and, while they won’t be able to cure the disease, they are the type of specialist who may be best equipped to manage your IPF symptoms. Not all pulmonologists are experts in IPF, however, so you may want to seek out pulmonologists who have experience treating patients with IPF.

3. **Ask about IPF treatment centers:**
   Another option to consider is IPF treatment centers. These are medical centers that specialize in treating this rare disease. There are a few located throughout the country, so you should ask your doctor if there is one near where you live.

   The Pulmonary Fibrosis Foundation has put together a list of IPF treatment centers available at the Medical Centers Specializing in PF Care page at PulmonaryFibrosis.org.

4. **Reach out to support communities:**
   There are a number of IPF support communities you can join for free. These allow you to connect with other people who may be able to relate to what you’re going through and who may have helpful tips on meeting the day-to-day challenges of living with IPF. (Connect with other people living with IPF. Learn about online support groups.)

5. **Talk to family and friends about IPF:**
   As with other serious diseases, many people living with IPF find that they can turn to their family and friends for support and help in facing the daily challenges of living with IPF. Of course, every family is
different, and it may take some time for you to figure out who to turn to and how much you can expect them to help.

The Caregiver’s Role

See how the husband and daughter of a person with IPF help to provide the support she needs to overcome the challenges of life with IPF. Watch other videos about IPF