



PILOT™ Patient Counseling Tools

End of Life Issues

If you have been diagnosed with IPF, your physician has discussed the course of the disease and the life-threatening nature of your condition. In addition to the complex medical management issues, there are also end-of-life issues that should be considered. Some of these are medical in nature, and some have to do with your possessions and estate. The purpose of this document is to provide a general overview, but these issues should be addressed in detail with your physician, your family, and your attorney.

ADVANCE DIRECTIVES

Advance directives are the documents that allow you to express your wishes to family, friends, and health care providers and help avoid confusion at the time when you may no longer be able to express them yourself. You control the advance directives, and you can modify them to account for changing circumstances. It is best to establish several documents and keep them updated so that you and your possessions are treated in accordance with your wishes.

WILL

A will is a legal document that directs the distribution of your estate after your lifetime. Generally a trusted friend or family member is named as executor, the person who oversees the fulfillment of the terms of the will. It is important that your will is legally sound, so that questions of taxes and distribution of your assets are clearly addressed. This serves both to make your intentions clear and to reduce controversy among your beneficiaries.

LIVING WILL

A living will is a set of instructions detailing your wishes regarding medical care. You have the right to accept or decline medical procedures, and a living will makes your intentions clear in case you are unable to communicate. Some of the issues that may come into consideration are:

- Life-sustaining mechanical support such as ventilators, respirators, and intubation
- “Do Not Resuscitate” orders that decline CPR
- Tube feeding and hydration
- Organ and tissue donation
- Comfort care such as nutrition, pain medication, antibiotics, etc.

Your living will should be signed, witnessed, and shared with those close to you as well as your doctor and hospital. Copies should be kept in easily accessible places.



DURABLE POWER OF ATTORNEY FOR HEALTH CARE

An individual can be named as your health care proxy, usually by establishing a durable power of attorney for health care. (A durable power of attorney for finances can be used to identify someone to manage your financial affairs.) Your health care proxy is the person entrusted to make medical decisions if you are unable to do so. As with the executor of your will, your health care proxy should be chosen carefully. There might be medical options that are not dealt with in your living will, and your health care proxy will be able to act on unexpected options in accordance with your wishes.

It is difficult to deal with end-of-life issues at any point in your illness, but many people have found these instruments to be a useful way of coping with the period ahead. Now is the best time to create or update these documents, before they are needed and to add to your peace of mind. These legal documents should be established with the help of an attorney. Be aware that laws vary considerably from state to state; this may be important if you have moved or your hospital is in a different state than your residence.

More information can be obtained from your health care professional or at some of these Web sites:

<http://www.pulmonaryfibrosis.org>

<http://www.cancer.gov/cancertopics/factsheet/support/advance-directives>

<http://www.uslivingwillregistry.com/individuals.shtm>