

Idiopathic Pulmonary Fibrosis A Caregiver's Guide



Being a caregiver means caring for someone's health and welfare with compassion and respect. This handbook will provide practical assistance on how to be a caregiver and how to get help and support.

Introduction

Caring for a person with idiopathic pulmonary fibrosis (IPF) is important, but it can also be challenging. The realization that you can help meet needs and solve daily problems can be deeply gratifying; chances are you will find new strengths within yourself.

The intense closeness that you have with the person who has IPF provides the opportunity to share a whole range of feelings. Your life as an IPF caregiver will probably be different from anything you've experienced before.

However, the care you provide your loved one can't occur when the caregiver is overwhelmed. You aren't alone in this experience. Help is there when you need it.

This booklet will provide some tips on being a caregiver and how to get help and support, if necessary, so that the process of caregiving is less stressful.

It is written in 2 parts.

Part 1
The caregiver

Part 2
Caring for your loved one

BEGINNING THE CAREGIVING JOURNEY

Accepting the diagnosis

IPF is a progressive disease; this means it gets worse over time. In all likelihood, you never expected someone you love to have IPF. It can be incredibly difficult to accept such a serious diagnosis. It helps to learn as much as you can about IPF. The more you know, the better equipped you are to deal with the diagnosis.

Most people experience a range of feelings, including anger, guilt, and sadness. These feelings will come and go unpredictably. They are a normal part of the process of acceptance.

It is important to recognize these feelings and not hide them from yourself. For some people, writing in a journal is helpful. Others find that it is good to share their feelings with friends or family members who may also be trying to accept the diagnosis. Sometimes, people find that talking with a therapist or other trained individual can be an important source of support.

Do not be hard on yourself if you find the process difficult. Gradually, as you care for your loved one, you may gain a better understanding of how to deal with it. As you do, you will be in a better position to help.

Making caregiving decisions

One reason caregiving decisions are hard is that they are unfamiliar. You have probably never had to deal with situations like these before. Also, you may worry about how they will affect your loved one. Sometimes they have to be made fairly quickly, which can add pressure and stress.

While it's good to talk with family members and get their thoughts, the primary person to involve is the patient. The patient's feelings may differ from everyone else's.

A step-by-step process

Turn a potentially overwhelming decision into smaller steps to make it easier to handle:



GETTING HELP AND SUPPORT

In general, caregivers have less stress when they have support. The adage, “Any burden is easier to bear when it’s shared” seems to hold true in this case. Sharing experiences with others in a similar situation can help you stay strong. Trying to be responsible for all the caregiving by yourself is not best for you or your loved one, so don’t hesitate to ask for help when you need it.

Family and friends

If you need a break, ask family or friends for help. This can be beneficial for several reasons:

- The patient will be more comfortable being cared for by someone he or she knows
- You will feel better leaving the person with someone you know
- Friends and family members may be more familiar with routines and preferences
- You can avoid the cost and difficulty of arranging for other care
- Being around more people expands the patient’s world and lessens the sense of isolation

How to ask for help

When family and friends want to help, ask when they can be available and what jobs they think they can do. Be specific about what you need.

Be Prepared	Have a list ready when people say “What can I do to help?”
Be Specific	For example, you could say, “Could you take Dad to his respiratory therapy appointments on Mondays?”
Be Positive	For example, you might say “I really appreciate it when you go to the grocery store.”
Offer Choices	“I need to get Uncle Bob’s prescriptions. Could you pick them up or stay with him while I go?”

When you get an answer from each person, note it on your list to make sure they have taken care of what you needed.

SUPPORT IS AVAILABLE TO YOU

When you think of caregiving, imagine a pyramid. You and the patient are at the top. The next level is family and friends who are there to support you. The third level is social services and outside assistance.



Social Services

Contact your Department of Social Services. They can provide a great deal of useful information about government resources.

HOME HEALTH AIDE

What a home health aide does

A home health aide (HHA) is a person trained to provide help to individuals in their own home. Most HHAs are registered with home care agencies that recruit and train their staff. Always make sure that both the agency and the HHA are registered. If you did not go through an agency, check that the HHA is fully insured and can provide you with references.

The HHA can provide daily care such as washing and dressing, fixing meals, and helping the patient to the bathroom. He or she may also be able to help with basic housekeeping tasks. You can let the HHA know what kind of care is most important.

You can decide how much time you'd like to have this help. You may want the HHA to come every morning for a couple of hours, a couple of times a week, all day, or maybe even overnight.

WHEN YOU NEED A BREAK

Locating a home health aide

Check with your local Department of Social Services to find a qualified home health aide (or find additional resources on pages 30-31 of this booklet) and to see if you can get help paying for one. Medicare may cover the cost for a few weeks after a person is discharged from the hospital. In certain situations, other resources may pay for extended care.

Be sure to discuss this with your loved one. It is important that he or she feel safe and comfortable with the person giving care. The home health aide must have the skills and patience to build a relationship, no matter how demanding the job may seem to be.



Respite care

Even if you have help with day-to-day care, you may need to have someone take over with full-time care for a short time. You may arrange for your loved one to stay in a residential home while you are away. This is respite care.

There are several options for respite care. Your choice will depend on your loved one's needs, how long you'll be away, and the cost of the services.

Respite care at home

Home is comfortable because it is familiar. The simplest solution is to ask your home health aide to provide full-time care for a short period of time. If you don't have a home health aide, ask your local Department of Social Services to recommend care agencies.

It may be helpful to know that insurance will cover some of this care.

CARE AND SUPPORT

Adult day care

Adult day care centers have the advantage of providing supervised care outside of the house so your loved one can interact with new people and not feel so isolated.

Residential care

It is possible to have your loved one stay for a short time in an assisted living facility or skilled nursing facility. This way you can relax, knowing that appropriate care will be available when needed.



SUPPORT GROUPS

Benefits of support groups

Getting together with others who are caring for a loved one with IPF can have a number of advantages. It can make a big difference in your attitude to know you are not alone and can help you feel less isolated. It may also be a good way to get useful information, such as learning how to move someone without damaging your back.

How to find a support group

- Ask your doctor, nurse, or social services. Support groups are often associated with hospitals and nursing homes
- Try contacting national organizations such as some of the ones listed on pages 30-31 to ask how to find a local chapter

HELPING YOURSELF



Take care of yourself—do not become exhausted

It may seem obvious, but it's easy to become tired by trying to juggle caregiving responsibilities with normal routines. For example, providing care while working can lead to exhaustion. If you become too tired, you're more likely to make poor decisions or to take out your frustrations on others. So take care of yourself; take time for yourself even if it means stepping out of your caregiver role for a bit.



Personal relaxation time

Take time to do something you find relaxing, whether it's reading a book, going for a walk, riding a bicycle, or anything else you enjoy. Quality time alone can make you feel refreshed when you return to caring for your loved one. Meditation and yoga help some people maintain emotional balance while caregiving. If you haven't tried these techniques, you may want to see if they help.



Stay in shape

Exercise is important for a number of reasons. First, it helps you stay healthy. Second, it helps to be in good shape physically to take care of your loved one. Third, exercise can benefit your emotional balance.

Summary of rest and renewal tips

- Do not try to do everything yourself
- Get a home health aide when you need help
- Arrange for other family members or friends to provide care
- Use a nursing home or assisted living facility for planned vacations
- Use adult day care
- Nursing homes or assisted living facilities are sometimes the best option

THE GRIEVING PROCESS

Before and after death

You may feel grief at many points throughout the illness.

It may hit you when you first hear that the patient has IPF. It may come later as you realize that you are spending your final days together. You will have many emotional milestones before and after the patient's death. Birthdays and holidays may be especially hard. You may feel sadness with each.



Although you cannot avoid grief, here are some suggestions to help you cope with it.

- **Being alone helps.** There may be times when you feel overwhelmed with grief. You may want to cry, sleep, go for a walk, or sit quietly. Do not feel guilty about needing to be alone
- **Embrace family and friends.** Accept invitations to spend time with loved ones. Leave if you need to. Reach out to someone if it seems too hard to go through it alone
- **Get plenty of rest.** Caring for a seriously ill person is tiring. Take time to rest and regain your physical and mental energy
- **Keep a routine.** Even though your life has changed drastically, keep your normal routine of eating healthily, exercising, and sleeping regularly

Get information from relevant national organizations. Find organizations on the Internet. See suggestions on pages 30-31.

TO BE A CAREGIVER

Being a caregiver means attending to the health and welfare of another person with compassion and kindness. It requires respecting your loved one's independence while providing help when it is needed.

Preserve dignity

- Listen closely and pay attention to the patient's worries and concerns
- Provide help on his or her terms. For example, tasks like dressing and bathing are personal and private—don't help unless requested
- Encourage your loved one to be as independent as possible
- Be understanding. Keep in mind that people with a progressive disease may feel frustrated

Help your loved one deal with each day

Try to remember:

- Being physically unable to do something does not mean the patient is mentally incapacitated
- Do not isolate your loved one or yourself
- Pay attention to the little things that bring you and your loved one pleasure every day
- Your loved one may feel afraid, isolated, or sad, and you can't make these feelings disappear



PROMOTE INDEPENDENCE

Most people want to make decisions regarding their own life. As an IPF caregiver, it is easy to get into the habit of doing too much. When you love a person with IPF, you want to help as much as possible. However, if your loved one is still capable of doing certain things, such as sending emails or fixing lunch, then encourage him or her to do so. Having some sense of independence makes it easier to receive care.

Be Nurturing

Encourage any effort at independence, no matter how small

Be Patient

Even if you can do something faster, be patient—let your loved one take care of it

Be Respectful

Don't treat your loved one like a child

Be an advocate

Because you are closest to the person with IPF, you are in the best position to speak on his or her behalf. Ask difficult questions that the patient needs to know the answers to but has trouble asking. Don't forget that you have a very important role on the healthcare team.

From the beginning, you will probably have the best idea of your loved one's condition. You may need to help different doctors share important health information about your loved one.

REINFORCE THE DOCTOR'S ORDERS

Part of your job as a caregiver is to reinforce the doctor's orders at home. This could mean reminding your loved one to take medicines at the proper time and making sure that all medical appointments are kept.



Know when to call the doctor

As with any lung disease, if your loved one has any of the following symptoms, you should call the doctor. Be sure to review these with the patient. Both of you should know when it is necessary to talk to the doctor.

- Increasingly difficult breathing during usual activities
- Increased coughing, a productive cough, or chest pain with coughing
- Mucus that is bloody, has an odor, or is green or yellow
- Swollen ankles or feet
- Increased fatigue
- Muscle cramps or weakness
- Shortness of breath that interrupts sleep
- New fever
- Any distressing symptom

Be sure to have a medical contact list where you can find it easily, such as on the front of the refrigerator.

END OF LIFE PLANNING

Talk with your loved one and the doctor about what changes in the progression of IPF mean in terms of treatment planning. It is important to discuss the plans before changes occur. However, you and your loved one can change your minds and revise your plans.

Because IPF is a progressive (worsening) disease, it is necessary to talk about the future and make plans for what will happen as your loved one's health declines. It is important to talk about the kinds of treatment he or she does not want.

Some people find it easier to approach these discussions as “what if?” planning:

- What if you cannot talk, write, or communicate?
- What if someone else needs to speak on your behalf?
- What if you are unable to breathe without a ventilator?
- What if the doctors recommend removing machines?

Caregivers may want to avoid these discussions because they are trying to be positive, but talking about these issues will allow both of you to feel more in control. You and your loved one should discuss these choices with the doctor.

Advanced care planning

Talking about advanced planning may be hard. It means admitting that the patient's health is declining. But, having a clear idea of the patient's wishes can bring peace of mind to both of you. You won't be left guessing if an emergency occurs.

Put it in writing

Advanced care planning involves written instructions that a patient gives for future medical care if he or she is unable to make decisions. Advanced care planning includes 2 important documents: a *Living Will* and a *Durable Healthcare Power of Attorney*, or *Healthcare Proxy*.

Some of the main issues a patient with IPF will want to consider when developing an advanced care plan will be:

- Naming a person who has the authority to make decisions if the patient is too sick
- Deciding what to do in an emergency
- Telling people what treatment options should be taken and which should not
- Stating preferences for time limits if devices such as ventilators, resuscitation, or feeding tubes are used

These issues should be discussed at regular intervals, since the patient's choices may change with time and circumstances.

MAKING LEGAL DECISIONS

Living Will

The patient may wish to consider a Living Will. This explains the patient's wishes for medical care in case he or she becomes unable to communicate. When developing a Living Will or Healthcare Proxy statement, everyone with IPF may wish to consult with a social worker or family lawyer about state legal requirements. State laws may differ on Living Wills, so you may wish to check with a lawyer about the Living Will laws in your state.

Healthcare Proxy

The patient may wish to give someone authority to make medical decisions on his or her behalf. The terms "healthcare proxy," "healthcare agent," and "surrogate" mean the same thing. Most people appoint a close friend or family member. Some people turn to a minister or lawyer. The designated person should be able to support the patient's decisions, understand the patient's treatment choices, and know what the patient values. The patient may wish to consult with a lawyer on this issue as well.

Among other things that a lawyer may recommend, a complete advanced care plan may:

- Cover what is to be done in different medical situations
- Name someone who can make decisions if the patient cannot communicate
- Be written down in a medical record
- Be available to any caregiver in the home, nursing home, or hospital
- Consult professionals

HOSPICE CARE

Eventually, caring for someone with IPF may become too difficult for anyone other than a highly trained healthcare professional. If this happens, hospice care may be an alternative.

Hospice care offers comfort care and support for patients and their families. Most of the time, it is provided at home, but in-patient care is also available.

Hospice care team members can include:

- Nurses
- Physicians
- Social workers
- Religious counselors
- Nursing assistants
- Volunteers
- Additional support staff to address physical, emotional, social, and spiritual needs

One of the benefits of hospice care is the support and guidance it provides. You may want to ask your physician whether hospice care is appropriate for your patient.

ADDITIONAL RESOURCES

Remember that you are not alone. More and more, people take care of loved ones during a progressive disease such as IPF. The following resources are available to you and the patient. Get in touch (and keep in touch) with these groups and ask for support.

Lung disease

Pulmonary Fibrosis Foundation
www.pulmonaryfibrosis.org

American Lung Association (ALA)
www.lung.org

To contact the ALA nearest you, call 1-800-LUNGUSA

National Heart, Lung, and Blood Institute
(Part of the U.S. National Institutes of Health)
www.nhlbi.nih.gov

Caregivers

National Alliance for Caregiving
www.caregiving.org

Compassion & Choices
www.compassionandchoices.org

Caregiver Action Network
www.caregiveraction.org

Visiting Nurse Associations of America
www.vnaa.org

Hospice

American Hospice Foundation
www.americanhospice.org

National Hospice and Palliative Care
Organization (NHPCO)
www.nhpco.org

Hospice Foundation of America (HFA)
www.hospicefoundation.org

Work

Family and Medical Leave Act
(US Department of Labor)
Toll-free number: 1-866-487-9243

Medicare

Centers for Medicare and Medicaid Services (CMS)
www.cms.gov
(For just Medicare info: www.medicare.gov)
Medicare Rights Center (MRC)
www.medicarerights.org

Social Security

Social Security Administration (SSA)
www.socialsecurity.gov

Insurance

American Council of Life Insurers (ACLI)
www.acli.com

Death and dying

Americans for Better Care of the Dying
www.abcd-caring.org

End of life planning

Funeral Consumers Alliance (FCA)
www.funerals.org

Caring Connections
www.caringinfo.org



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