



# The Caregiver's Journey in ILD

Helpful tips for the road ahead  
as you begin caring for your loved  
one with a chronic interstitial lung  
disease (ILD) in which lung fibrosis  
continues to worsen

Not actual patients

# Introduction

Someone you care deeply about has a chronic (long-lasting) ILD that continues to worsen (progress). Becoming their caregiver is an important and gratifying job, but it can also be very challenging. Being a caregiver means caring for the health and welfare of another person with compassion and kindness. It also means tending to your own emotional and physical needs. **This booklet will provide tips for both.**

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# Key facts about ILD

Interstitial lung disease, commonly referred to as ILD, is a term used to describe lung disorders that cause inflammation and/or scarring around the air sacs of the lungs, called the alveoli. There are a variety of potential causes of ILD and some types of ILDs have no known cause. Some people who develop ILD will have scarring, also called “fibrosis” that will continue to worsen over time.



## Interstitial Lung Disease

- Scarring and/or inflammation develop around the tiny air sacs in the lungs, called alveoli
- The space around the alveoli is known as the interstitium



## Lung Fibrosis

- Scarring of the lung tissue that can worsen and spread over time
- Damaging to lung structure
- Making it more difficult for your lungs to work properly



## Progressive

- Declining lung function over time
- Worsening of symptoms
- Worsening lung fibrosis

## Progressive ILDs

Although more than 200 different interstitial lung diseases have been identified, not all are so aggressive. Some types that are more likely to produce this type of progressive scarring include:

Idiopathic interstitial pneumonias (IIPs)

Autoimmune ILDs, like scleroderma-associated ILD

Hypersensitivity pneumonitis

Sarcoidosis-related ILD

Exposure-related ILD

# Your role as caregiver is essential



## Be an advocate

As a caregiver for someone with ILD, you support comprehensive care for them in several key areas.

- You know your loved one best, which means you are in the best position to speak up on their behalf, and to ask the difficult questions
- One of your jobs is to seek out the appropriate care—at the appropriate time

## Encourage independence and preserve dignity

It's a delicate balancing act, but as much as you may want to help your loved one, you want them to be as independent as possible. It's good for both of you.

### **Be nurturing.**

Encourage any effort at independence, no matter how small.

### **Be patient.**

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

### **Be respectful.**

Treat your loved one with dignity.

Your loved one should be included in all decisions regarding their care. Treat them with respect, and help them maintain a sense of control and privacy whenever possible.



**Listen closely and pay attention** to your loved one's worries and concerns



**Provide help on their terms;** tasks like dressing and bathing are personal and private—don't help unless requested



**Be understanding.** Keep in mind that anyone with a progressive disease may be frustrated at times

# Emotional support and day-to-day care

## Staying connected

While you may now have a patient/caregiver relationship, the roles you had before are still important. If you are a wife caring for your husband or vice versa, it's important that you continue to relate as spouses.

Make sure neither of you become isolated

Try to pay attention to little things that bring each of you pleasure

Offer emotional support if your loved one feels afraid or depressed about their disease

### Remember:

Keep a list of all the patient's doctors and a list of medications where you can find it easily, such as on the refrigerator or on your phone.



## Monitor their condition

It can be very helpful for you or your loved one to keep a daily log of their condition. Note any worrisome changes and share with the rest of the healthcare team. To that end, it's essential that both you and your loved one know when to call the doctor, including for:

- Increasingly difficult breathing
- Increased coughing or chest pain
- Mucus that is bloody, has an odor, or is green or yellow
- Swollen ankles or feet
- Increased fatigue
- Fever
- Loss of appetite
- Muscle cramps or weakness
- Shortness of breath that interrupts sleep

## Manage their schedule

Another important aspect of caregiving is to help guide your loved one's daily schedule:

- Make sure medications are taken as directed
- Refill prescriptions before the medications run out
- Help with scheduling medical appointments
- Arrange transportation to doctors and lab visits

# Palliative care



Palliative care is a general term used to describe the treatment of symptoms and stress associated with a progressive disease like ILD. **The goal of palliative care, which is not to be confused with hospice, is to improve or maintain a patient's quality of life.** Some examples of palliative care include:



Medications to help address specific symptoms



Oxygen therapy to help relieve shortness of breath and improve sleep



Interventions that can help reduce stress, depression, and pain

Palliative care is considered a key component in supportive treatment and may be considered **"routine medical management"** by your doctor and insurance provider.

## Oxygen use may increase with disease progression

As breathing becomes more difficult and oxygen use increases, **your loved one may require a higher level of care.**

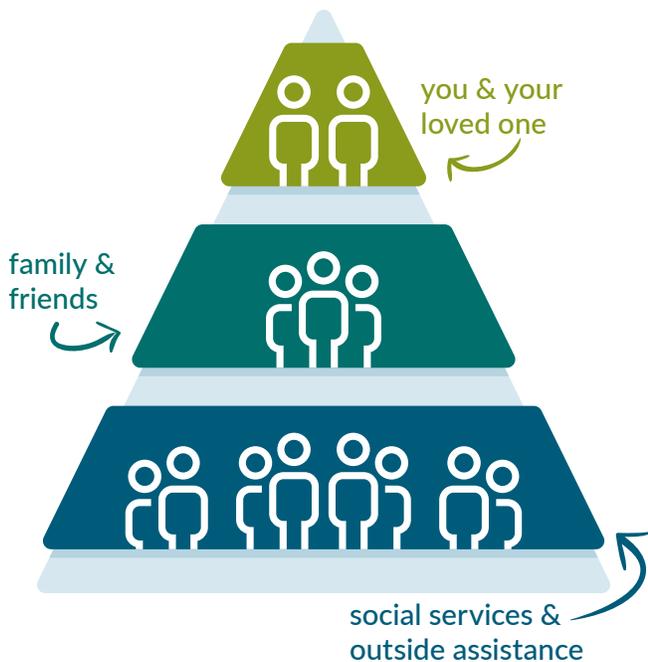
- When your loved one is "early" in their disease, no supplemental oxygen may be needed
- As they progress, they may need oxygen with activity, but not when at rest
- Eventually, constant oxygen use might be needed during activity, when your loved one is at rest, or asleep
- Advanced oxygen supplementation might be necessary if your loved one needs high-flow oxygen or the portable concentrator delivery system is insufficient

## Oxygen: Points to consider

- Guidelines recommend starting oxygen therapy when blood levels fall below 89%. Medicare and other insurers won't cover oxygen if blood levels are at 89% or higher, so low oxygen levels must be verified and documented
- Oxygen is written as a prescription by a doctor
- A prescription for oxygen may also be determined by a walk test

# Getting the support you need

In general, caregivers have less stress when they have help. Trying to be responsible for all of the caregiving by yourself is not best for you or the person you are caring for, so don't hesitate to ask for help.



**Think of caregiving as a pyramid.** You and your loved one are at the top. The next level is family and friends who want to help you. The third level is social services and outside assistance.

## Caregiving decisions can be stressful

One of your most important roles will be making decisions regarding your loved one's health. **Be sure to include your loved one whenever possible.** Getting input from doctors and family members is helpful, but ultimately, you should be making decisions that are aligned with your loved one's wishes.

Smaller steps make it easier. **Sometimes it helps to approach a big and potentially overwhelming decision by breaking it down:**

- Step 1** Identify a specific goal
- Step 2** Get information
- Step 3** Find alternatives
- Step 4** Make a plan
- Step 5** Give your decision time to work
- Step 6** Evaluate how well it's working

# Asking family and friends for help



## When you need a break, asking family or friends to pitch in can be beneficial:

- Your loved one will be more comfortable being cared for by someone they know
- You will feel better leaving them 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 outside care

Being around other friendly faces can help your loved one feel less isolated



## How to ask for the help you need



### Be prepared.

*Have a list ready when people ask how they can help*

### Be specific.

*“Could you take Dad to his respiratory therapy appointments on Mondays?”*

### Be positive.

*“I really appreciate it when you get groceries for Mom.”*

### Offer choices.

*“I need to get Uncle Bob’s prescriptions. Could you pick them up or stay with him while I go?”*

# Social services and outside assistance

## Home health aides

A home health aide (HHA) is trained to help people in their own home and can provide daily care such as:



Washing and dressing



Fixing meals



Helping your loved one to the bathroom



Light housekeeping

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 do not hire an HHA through an agency, check that the HHA is fully insured and can provide you with references.

Consider how often you want an HHA and how long each visit should be. For example, your loved one may require at-home assistance every morning, several times a week, or sometimes overnight.

### Paying for a home health aide

- Medicare will sometimes cover HHA costs for a few weeks after a hospital or rehab discharge
- Your state Department of Aging may pay for extended care
- Otherwise, private funds would need to be used



### Remember:

Assistance may be available to help pay for these services.

# Other types of professional help



## Respite care

**Respite care is full-time care for a short period**, providing you with a respite from day-in and day-out caregiving. Home is usually the most comfortable place for your loved one to stay when you are unavailable. Often, the simplest solution is to ask your HHA if they can provide respite care.

**You may be able to access free services**, such as transportation, home care and maintenance, and home support. Check with your local government offices, volunteer organizations, and senior services to see what may be available in your community.



## Adult daycare

Adult daycare centers provide **supervised care outside the home**, so your loved one can interact with new people, make friends, participate in activities, and feel less isolated.



## Residential care

Another option is to have the person you are caring for 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 as needed.

# Caregiver support groups

## A helpful way to learn more about ILD, ask for advice, and find resources

While being a caregiver can be a rewarding and gratifying experience, it can also be both physically and emotionally draining. In addition, it is a role that is often lonely and isolating. Caregiver support groups can:

- Help to reassure and validate your experiences
- Help you connect with others who are in a similar place
- Empower you to share your feelings—both positive and negative—about caring for someone with ILD

Meet in person, by phone, or online



## Finding a support group

Do an online search for local groups

The Pulmonary Fibrosis Foundation ([pulmonaryfibrosis.org](http://pulmonaryfibrosis.org)) lists support groups by state

Inspire.com has a “Caring for Pulmonary Fibrosis” community

Contact national organizations (see those listed on page 32), to connect with a local chapter

Ask your healthcare professional or local Department of Social Services to suggest groups

Spiritual and religious organizations have faith-based support programs

# Caring for YOU



## Taking some “me” time

When you are caring for someone, you may think that your needs are not the top priority. Or, you may feel that you’ve immersed yourself so fully into your caregiver role that there’s no longer any time for you.

**Surprisingly, the reverse approach is more effective.**

Caring for your own needs and desires can give you the strength you need to carry on. Below are some ways you can take care of yourself.

### **Pace yourself.**

- It may seem obvious, but it’s easy to become overly tired. If you become too tired, you’re more likely to make poor decisions or to take out your frustrations on others

### **Make time to enjoy activities or hobbies that you find relaxing.**

- Quality time alone can help you feel refreshed
- Meditation and yoga can help you find emotional balance
- Daily exercise will help you stay in shape, both physically and emotionally

## Rest and renewal reminders

Do not do everything yourself

Ask family members and friends to help with various tasks such as preparing meals

Get a home-health aide when you need support

Use a nursing home or assisted living facility for vacations

Encourage adult daycare attendance

For full-time care, nursing homes or assisted living facilities may be the best options

# Everyone experiences grief

**Grief is a process**, and it's different for everyone. It may first hit you when you learn your loved one has this disease, and later as you realize you are likely spending some of your final days together. Birthdays and holidays may be especially hard—and it's normal for both you and the person you are caring for to feel sad.

Although you cannot avoid your gloomy feelings, here are some suggestions that may help you feel better:

## 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.

## See family and friends

Accept invitations and spend time with those you love and care about. Reach out to someone close if you're feeling down.

## Get plenty of rest

Caring for a seriously ill person is tiring. Take time to rest and regain your physical and mental energy.

## Stick to a routine

Even though your life has changed, try to stick to a routine of healthy eating, exercise, and regular sleeping.

## Learn when to get help

If you are feeling extremely depressed or anxious, you may want to seek help from a professional therapist.

# Preparing for the future



## Living will

Many adults have a living will or an advance directive, which details the medical care they would want to receive if they become unable to communicate

State laws may define when a living will goes into effect and may restrict the medical interventions to which it applies

Be sure to speak with a lawyer about the living will laws in your state

## POLST form

- POLST is an acronym for “Physician Orders for Life-Sustaining Treatment”
- It is a short document that provides medical orders to healthcare providers in an emergency
- POLST forms vary from state to state, but the key information is similar
- The POLST form must be signed by the primary physician or another doctor to be legally valid

## Durable Healthcare Power of Attorney (POA)

- It's also important for your loved one to consider signing a Durable Healthcare Power of Attorney document or select a healthcare proxy. This is the person who makes medical decisions when your loved one is no longer able to do so
- Most people appoint a close friend, family member, minister, or lawyer
- The designated person should be able to support your loved one's decisions, understand their treatment choices, and know what they want



### Remember:

Encourage your loved one to speak with an attorney and their physician about all these documents.

# Talking about end-of-life planning

## It's an important conversation

Creating end-of-life or advance care plans may be difficult because it means admitting that your loved one's health is declining. **However, having a clear idea of their wishes can also bring peace of mind to both of you.** You won't be left guessing what they would prefer if an emergency occurs.

- Since these conversations can be difficult, some people find it easier to break the ice with "what if" questions (eg, "What if someone else needs to speak on your behalf?")
- You will want to talk to your loved one and their doctor about how worsening symptoms may indicate IPF progression, and how that may affect treatment planning
- Make sure your loved one understands they can always revise their plan, but it's important to have an initial plan in place

## Put it in writing

Advance directives should be in written form. Some of the topics that should be addressed include:

Naming a person who has the authority to make decisions if they are too sick

Deciding what to do in an emergency

Acceptable treatment options and medical interventions

Time limits for use of ventilators, resuscitation devices, or feeding tubes

# Creating an advance care plan

## The completed advance care plan should:

**Name the healthcare proxy**  
(ie, the person who has been granted decision-making authority)

**Provide acceptable treatments and medical interventions** in both routine and emergency medical settings

**Be available to any caregiver** in your loved one's home, nursing home, or hospital

## Ask an attorney to review

Advance care plans should be reviewed by an attorney to ensure your loved one's wishes will be followed and that the documents are legal and binding. A lawyer may also be able to assist with wills, life insurance policies, and other financial matters depending on your loved one's needs.

## Hospice care

As the disease progresses, your loved one may want to enter hospice care, which offers end-of-life comfort care and support for patients and their families. Most of the time, hospice care is provided at home, but inpatient hospice may also be an option.

Hospice care is a key Medicare benefit. State Medicaid programs include hospice benefits, as do most private health insurance plans, although coverage varies.



### **Remember:**

Check with your insurance provider for coverage information.

# Helpful Resources



**Lungs&You®**  
lungsandyou.com

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## Other Online Resources\*

**American Association  
of Retired Persons (AARP)**  
aarp.org/caregiving

**Arthritis Foundation**  
arthritis.org

**CaringBridge†**  
caringbridge.org

**Family Caregiver Alliance**  
caregiver.org

**Foundation for Sarcoidosis Research**  
stopsarcoidosis.org

**Inspire.com (Caring for PF community)**  
inspire.com

**Lotsa Helping Hands†**  
lotsahelpinghands.com

**Pulmonary Fibrosis Foundation (PFF)**  
pulmonaryfibrosis.org; 1-888-733-6741

**PF Warriors**  
pfwarrior.com

**Scleroderma Foundation**  
scleroderma.org

**Sjögren's Syndrome Foundation**  
sjogrens.org

**The Myositis Association**  
myositis.org

**VA Caregiver Support**  
caregiver.va.gov

\*These are third-party resources that are not owned, managed, or endorsed by Boehringer Ingelheim.

†These websites have mobile apps as well.

# Helpful Resources

## Mobile apps\*

### Carezone

A care profile for the person receiving care. Includes a task list and journal that you can share with family/friend helpers. Medication tracking and file sharing services are also available. **Free for iPhone, iPad, and Android;** [carezone.com](http://carezone.com)

### Cozi

Manage the family schedule, organize shopping/to-do lists, plan meals, and set reminders. **Free for iPhone, Android, Blackberry, Windows 8.1**

### Finovera

Keep track of monthly bills and bank accounts. Includes payment reminders and bill retrieval from company Web sites. **Free for iPhone and Android**

### MediSafe

Securely keep track of multiple medications, set reminders, and create reports about how well your loved one sticks to their regimen. **Free for iPhone and Android**



## Books for caregivers\*

### The Caregiver's Survival Handbook

*by Alexis Abramson, PhD*

A supportive, reassuring, and practical guide to getting help, fostering independence, and balancing the demands on your own time and resources.

### No Saints Around Here: A Caregiver's Days

*by Susan Allen Toth*

An intimate account of the realities of meeting the challenges of caring for a loved one.

### The Caregiving Wife's Handbook: Caring for Your Seriously Ill Husband, Caring for Yourself

*by Diana B. Denholm*

Profiles of 6 women in caregiving situations who offer survival tips and personal anecdotes.

### Elder Care Assistance: A Practical Guide Covering Health, Financial and Legal Considerations

*by Sandy Myerson*

A concise, straightforward guide to caregiving for aging parents, written in a systematic, logical format.

### CAREGIVING Ready or Not

*by Charles Puchta*

Clear, unbiased information and insight to help caregivers and care receivers make informed decisions.

### They're Your Parents, Too!: How Siblings Can Survive Their Parents' Aging Without Driving Each Other Crazy

*by Francine Russo*

A psychological and practical roadmap through caregiving.



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# You've taken on a big role.

Caregiving is an important responsibility.  
Be sure to take good care of yourself while  
taking care of your loved one.

For inspiration and information,  
visit [LungsandYou.com](https://LungsandYou.com)

