

CAREGIVING FOR A PATIENT LIVING WITH
PULMONARY FIBROSIS

A guide for family and friends



FIND IT FAST

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Have questions that aren't answered in this guide?



Contact the PFF Help Center at
844.TalkPFF (844.825.5733) or
help@pulmonaryfibrosis.org

CAREGIVING: A COMFORT AND A CHALLENGE

Whether you're a spouse, partner, child, other relative, or friend, caring for someone living with a serious illness is a substantial responsibility. Caregivers take many different roles: some are actively engaged in medical or practical care, while others may handle financial tasks or focus on emotional support. If you manage your loved one's medications, talk to doctors and other healthcare providers on their behalf, help bathe or dress them, or take care of household chores or bills, you're a caregiver.

It's rewarding to be able to support your loved one's daily needs with compassion and kindness, but the demands of caregiving can be physically and emotionally draining. If you're caring for a patient living with pulmonary fibrosis (PF), the tips in this booklet can help you be a more effective caregiver while taking care of yourself, too.

First steps in caregiving

A solid foundation for caring for a patient living with PF begins with understanding the disease and the impact it will have on the patient. Because PF is a complex disease, your loved one may have a number of healthcare providers involved in their care. You may need to talk to several of your loved one's physicians to get the full picture of what to expect and have your questions answered.

Here are some important things you, your loved one, and your support team should know about PF:

1. Pulmonary fibrosis is scarring of the lung tissue that is irreversible.
2. Lung damage from PF makes it difficult for the lungs to expand, and to transfer oxygen to the body.
3. PF is progressive and will get worse over time.
4. Each patient living with PF experiences the disease in their own way. Symptoms, the disease course, and progression are difficult to predict.
5. Patients living with PF can have other related conditions, as well as complications that can develop as a result of PF.

The PFF can help you learn more about PF and the impact the disease may have on your loved one. Visit the "Understanding PF" tab on the PFF website, pulmonaryfibrosis.org, or contact the PFF Help Center (844.825.5733, help@pulmonaryfibrosis.org) for printed educational materials.

In addition to learning as much as you can about PF and how it will affect your loved one, the following are some other aspects of caregiving you'll want to explore as early as possible:

- Find out about your loved one's **health insurance** and what their plan covers. See if they're eligible for public programs such as Medicare and Medicaid.
- Talking about **finances** can be sensitive, but you'll need to have a solid understanding of your loved one's assets to plan for housing, healthcare, and other expenses. Ask them to review their bank accounts, investments, insurance coverage, loans, and other assets that can be used to cover potential care needs.
- If your loved one hasn't created **legal documents** relating to their care, such as an advanced directive or healthcare proxy (see "Plan for the future" section, page 7), talk to them about doing so now so their wishes can be carried out.
- Half of all caregivers are employed full or part time. If you're one of them, consider how you'll **balance employment and caregiving**. Some jobs and employers are more flexible than others, so see if flextime, working from home, or reduced hours are options. Explore the provisions of the federal **Family and Medical Leave Act** (FMLA) and your state's family leave laws to see how they may apply to your situation. Remember, FMLA time is unpaid. However, a few states require paid family leave.



Spotlight on safety

As your loved one's physical needs change, some simple additions like grab bars, shower seats, and night lights can reduce risks at home. Visit aarp.org/homefit for a guide to making homes safer. If you or others are caregiving from a distance, consider how technology like personal emergency response systems, remote monitoring devices, and mobile apps with medical records might help. Make sure all your loved one's caregivers have a list of healthcare providers' contact information, insurance providers, neighbors, and medication names and dosages.

Profiles in caregiving



RICK TIDWELL

"We're a great team," says caregiver Rick Tidwell, describing the division of duties he and his wife, Heather Kagel, made after she was diagnosed with idiopathic pulmonary fibrosis. "Heather and I each know our strengths and weaknesses and

worked with them. For instance, I'd take care of administering most of her medication—I've probably crushed 30,000 pills by now—and she'd take care of ordering it."

Heather, who had a double lung transplant in 2019, is doing well and is largely independent these days—but in the time before and just after her surgery, Rick's caregiving responsibilities multiplied. "PF is a progressive disease, and with the caregiver it's also progressive," he explains. "You'll add more responsibilities as time goes on."

A passionate runner, Rick managed to get his miles in even during the most challenging times. "It's important that caregivers continue to do some of the things you're used to doing, even if you have to find a different schedule," he says.

Heather, who is a volunteer, praises Rick's emotional support. "There were days when things felt too hard, and Rick held me when I cried and didn't try to talk me out of my emotions," she says. "That's important for a caregiver to know: sometimes you just have to let the patient express their feelings and unload."

RICK'S TOP TIP: Be patient with each other. Know that your loved one's personality may change a little bit and you just need to go with the flow more than you normally would.

Focus on team-building and communication

No one person can do it all. You'll need to ask for help from many sources: professionals, people you hire to provide services, family members and friends, neighbors, and community-based organizations. To keep communication lines open with everyone and work effectively as a team:

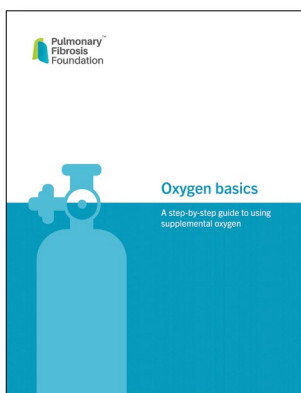
- **Remember faraway friends and family can still help.** Even if they're not nearby, family and friends can assist with tasks ranging from technology assistance to bill paying or meal organizing. The deeper and wider your team, the better you'll be able to deal with emerging issues, and the more likely you'll be to have help when you need it.
- **Respect your loved one's wishes.** As you create your initial caregiving plan—and as the plan changes over time to meet your loved one's evolving needs—always seek the participation, knowledge, and consent of your loved one.
- **Think about the big picture.** Consider what your loved ones' needs are now, and what they, and you, might need in the future. Make a list of these possibilities to refer to as you put your care team together. Remember that help can come from professionals and community-based organizations or agencies, as well as from family and friends.
- **Try to get all family members involved.** If your family problem-solves together, consider holding a meeting to discuss your loved one's healthcare, living arrangements, how to share caregiving tasks, and how to pay for what insurance doesn't cover. Before starting, consider who should lead the conversation, what your shared goals are, and what you're willing to take on.
- **Talk to family members separately when necessary.** If meetings aren't your family's style, try to find a way to include and communicate with everyone, even if some are more actively involved in caregiving than others.

Be organized and actively involved

As a caregiver, you'll likely participate in multiple aspects of your loved one's healthcare and daily life. To stay organized and keep things running smoothly:

- **Be actively involved in your loved one's diagnosis and treatment journey.** Remember that patients living with PF often find healthcare information confusing and challenging. Your support may help reduce anxiety for both of you.
- **Accompany your loved one to medical appointments.** Take along a list of questions you both want to ask and take notes. As a caregiver, you understand what your loved one experiences, so be prepared to advocate for them if you feel it's necessary.

- **Learn about the members of your loved one's healthcare team.** Make sure you understand their roles and whom you should contact when you have questions between appointments. Keep providers' contact information—especially emergency numbers—easily accessible.
- **Maintain a current list of all your loved one's medications.** Include all **prescription medicines** and over-the-counter supplements, and print copies to share with healthcare professionals and other members of your caregiving team.
- **Know how to operate medical equipment.** Become familiar with the devices your loved one uses, including a pulse oximeter and oxygen equipment. Keep instruction manuals and customer service numbers handy.
- **Help your loved one make positive food and exercise choices.** Know when to provide extra motivation for a **healthy diet and exercise program**—or join them if they need support.
- **Make to-do lists and set a basic daily routine.** Keep in mind that things won't always unfold as scheduled. The day may shift if your loved one isn't feeling well or if it takes longer than anticipated to complete certain tasks. It's okay to revise your routine.
- **Plan ahead for appointments, outings, and trips outside the home.** Allow extra time to get ready. Consider what accommodations may be needed, like dropping your loved one off while you park. Pack snacks, water, a pulse oximeter, and any medications your loved one will need while away from home. Know how much portable oxygen you'll need for each trip.



Managing oxygen needs

If your loved one uses supplemental oxygen, monitoring and planning for it will be an important part of your caregiving. A PFF patient education booklet, **"Oxygen Basics,"** is available on the PFF website. Contact the PFF Help Center (844.825.5733, help@pulmonaryfibrosis.org) for a printed copy.

Profiles in caregiving

DEBBIE (HERNDON) KLEIN



When Debbie Klein's late husband, Steve Herndon, was diagnosed with pulmonary fibrosis, "We decided early on that we were going to live with PF, not die with it, so we never stopped going places," says Debbie.

"Even though everything we did took extra effort, my husband always thanked me after an outing. We went to our seventh Jimmy Buffett concert, dressed as always in our concert garb, and even attended Boise State University football games until a month before Steve passed away in 2016."

Debbie, now a dedicated PFF volunteer, continues to lead the Idaho Pulmonary Fibrosis Support Group she and Steve joined during his illness. She's learned a lot about the disease and caregiving from her fellow support group members—and from the PFF website. "From disease education to clinical trial results, from tips on living with pulmonary fibrosis to fundraising and its importance, the PFF has a wealth of information I wish I'd discovered sooner," she says.

The printable **PFF Friends and Family Card**, which explains PF in easy-to-understand terms, is a recent innovation Debbie highly recommends. "It can be hard for people to grasp what PF patients go through when they look good but don't feel good," she says. "I wish I'd had the cards to give to people around us."

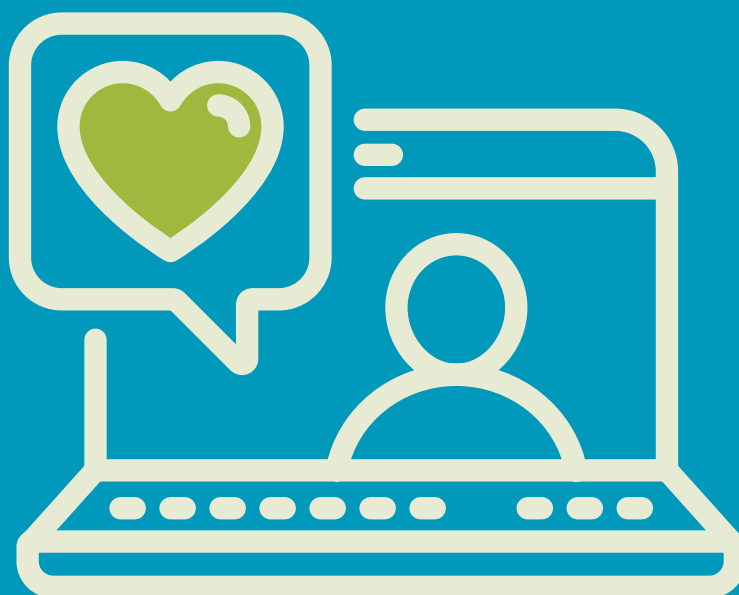
DEBBIE'S TOP TIP: Don't forget to ask for and accept help. Have some tasks and errands stored up in your mind, so you can answer with something specific when somebody says, "Is there anything I can do for you?"



Take care of yourself

Staying on top of your own physical and emotional health is essential to helping you care for your loved one. It doesn't just make you feel better—it can help protect you from the negative health outcomes caregivers often experience. So that you can best care for your loved one:

- **Pay attention to how you feel.** Learn to recognize the early signs of stress, depression, and anxiety in yourself. Irritability, excessive fatigue, apathy, substance abuse, and weight gain or loss are among the symptoms of caregiver burnout. Seek professional help if you need it. This will benefit both you and your loved one.
- **Let others help.** Accept the assistance of friends, neighbors, and others when it's offered. Most people want to help but are unsure what's needed. Keep a list of ways that others can lend a hand, like running errands, picking up groceries, or making a meal. Let them choose how they'd like to help.
- **Tend to your physical needs.** Eat healthfully, drink plenty of water, exercise, and get enough sleep.
- **Keep up with your own medical appointments.** Staying up to date on your healthcare helps protect you and your loved one, especially after returning home.
- **Look for supportive resources in your community.** You may find it helpful to have meals delivered or get assistance with shopping or light housework. Many areas also have adult daycare or respite care services that can give primary caregivers a break from their caregiving duties. You can find services in your community by dialing 211 on your phone or by contacting Eldercare Locator at 800.677.1116 or eldercare.acl.gov.
- **Make time for yourself.** Keep doing some of the things that are important to you and that preserve your social connections. Participate in a hobby, get a massage, call someone you enjoy chatting with, read a book, have lunch with friends—do whatever gives you pleasure, reduces stress, and helps you relax. If you're concerned about leaving your loved one alone, ask a friend or family member to stay with them, or consider respite care while you're away.
- **Take aim at stress.** Consider exploring stress-management techniques like meditation, yoga, or deep-breathing exercises.
- **Find supportive listeners.** Establish a network of friends and relatives you can talk to when things are hard. Consider joining a **support group for caregivers**, which provides a safe space to share ideas with others experiencing the same things.



Join our caregivers' support group

The PFF's telephone-based support for caregivers, "PFF Caring Conversations," meets on the first Tuesday of every month. Visit pulmonaryfibrosis.org/zoom for details.

- **Prioritize.** If you can't find time to embrace all or most of these forms of self-care, focus on the area in which you feel you're at most risk. For example, if you have health problems of your own, seeing healthcare providers regularly may be your priority. If you're generally healthy but feeling depressed, talking to a doctor or therapist might be most important.
- **Be gentle with yourself.** Let go of guilt—recognize that there's no such thing as a perfect caregiver. Acknowledge the many things you do well every day, as well as your own limits. If you realize that your best effort isn't enough to meet your loved one's needs, it's time to change the situation and ask for help.

Discover your new normal

Living with a chronic disease like PF means life will change. Together, you and your loved one will build a new normal that will blend familiar routines with new habits and relationship dynamics. To adapt to your loved one's changing needs as the disease progresses:

- **Stay flexible.** Identify the things you can control while recognizing that some things will be outside your influence.

- **Encourage independence.** While you'll likely take on additional chores and some tasks your loved one used to do, it's important that patients living with PF continue to do as much as they can for themselves. As your loved one's health allows, consider new ways of working together—for example, your loved one might make the grocery list before you do the shopping or pay the bills while you do laundry.
- **Find new ways of connecting.** As your loved one's disease progresses, look for leisure activities you can enjoy together that take into account your loved one's changing abilities and energy levels. When appropriate, get other family members and friends involved.
- **Make room for emotions.** Your loved one may feel anger, sadness, anxiety, or impatience at different times. Many chronically ill patients experience grief, isolation, and a sense of loss. It's important to acknowledge and talk about difficult emotions. Be aware of signs of anxiety and depression in your loved one—if necessary, seek professional help through your loved one's physician or community services.

Profiles in caregiving



STEPHANIE GOLDEN

Like many pulmonary fibrosis patients, Olga Henderson wasn't diagnosed until late in her disease course. Her daughter, Stephanie Golden, was her primary caregiver during the six months before Olga passed away in 2018.

"My mom moved in with me and I organized her medications, helped her with nightly bathing, made sure she had good meals, and provided emotional support," says Stephanie, whose brother and sister-in-law took care of managing Olga's oxygen deliveries and taking her to doctors' appointments.

Although the rapid progression of her mom's disease meant "I was on autopilot and didn't do a great job of taking care of myself," Stephanie says, "I did rely on my faith for strength and stayed spiritually connected with friends."

After Olga passed away and Stephanie's coworkers made a gift to the Pulmonary Fibrosis Foundation, "I truly learned what the PFF had to offer," Stephanie says. "I set out to learn more about this rare, dreadful disease, so I could advocate for others traveling this devastating road."

Becoming a PFF volunteer "became an avenue through which I could channel my grief by advocating for others walking a similar journey, facilitating increased awareness of PF, and encouraging donations in the fight for a cure," she adds. "I want to make an impact on newly diagnosed families."

STEPHANIE'S TOP TIP: Get involved in the PFF or support groups. For me, it's been a way of sowing seeds of peace in my heart. Being as helpful to others as I can helps reconcile my grief.

Explore palliative care

Although it's often confused with hospice, which focuses on end-of-life support, palliative care is a treatment option that helps patients feel their best during the entire course of a serious disease. **Learn what palliative care involves**—and consider seeking it for your loved one.

- Palliative care focuses on providing relief from the many **symptoms and stress** PF can cause. Treatment is usually symptom-focused, and the goal is to improve patients' and their caregivers' ability to enjoy life. A palliative care team usually consists of specially trained doctors, nurses, social workers, and others who work together with the patient's existing care team to provide an extra layer of support.
- Palliative care can **begin at any time** and occur at the same time as all other treatments, including participating in research studies, pulmonary rehabilitation, and lung transplant evaluation. In one study, patients with serious illness who received palliative care lived longer than those who did not.
- Palliative care teams help patients living with PF and families **throughout the disease journey**, help patients understand their options as the disease progresses, and assist patients and families in deciding how the patient would like to be cared for as the end of life approaches.
- The palliative care team also addresses physical, emotional, social, and spiritual **issues for caregivers**. By providing guidance and resources to help caregivers remain mentally and physically healthy, palliative care helps caregivers better support patients.
- Palliative care can be given in **many settings**: hospitals, clinics, virtually, or in the home. If you or your loved one could benefit from more support in managing PF, ask your loved one's care team for a palliative care referral. Most major forms of insurance (including Medicare and Medicaid) cover palliative care.
- Learn more at getpalliativecare.org.

Guard against respiratory infections

Take these steps to help prevent respiratory infections in your loved one:

- **Stay up to date with vaccinations.** Make sure everyone in the household over six months in age has a flu shot every year. Stay current with COVID-19 immunizations. Obtain a pneumonia vaccine if you're over 65 or have certain health conditions (check with your healthcare provider if you're unsure).
- **Keep it clean.** Wash your hands or use alcohol-based hand sanitizer frequently.

- **Avoid large crowds.** Keep your loved one away from big groups of people whenever possible.
- **Know when to say no.** It's all right to turn down visits from family and friends, stay away from crowded areas, or avoid anything else you feel is unsafe for your loved one. You're the best judge of what's okay or not.
- **Practice COVID-19 safety.** Continue to use face coverings and physical distancing until the prevalence of the COVID-19 virus in the community is significantly reduced. Learn more at pulmonaryfibrosis.org/covid19.
- **Watch for symptoms.** If your loved one develops a cough, cold, or flu, notify their healthcare provider right away.

Plan for the future

It can be hard to talk about what will happen as your loved one's PF progresses, but it's important to have those conversations as early as possible after their diagnosis. To make a plan for the future:

- Understand that as the disease unfolds, your loved one may need a **higher level of care** than you're able to provide. Ask your loved one's physician about the kind of care your loved one may need, and learn more about options available in your area.
- **The Conversation Project** provides downloadable guides for making **end-of-life care decisions** and selecting a healthcare proxy.
- Learn about **advance directives** like living wills, healthcare power of attorney, and physician orders for life-sustaining therapy (POLST). For more information, visit caringinfo.org and polst.org.
- In partnership with FreeWill, the PFF offers a **free resource** for making a will.
- Once you've prepared these documents, keep them where they're **safe and easy to find**. You can also add them to your loved one's medical record at the clinic where they receive care.
- Consider discussing your loved one's **end-of-life care decisions** with family members. Share any documents your loved one has prepared so that family members understand your loved one's wishes.
- With your loved one's input, select someone to be the **decision maker** if you're no longer able to do so. Make sure that person is comfortable in this role, then talk to them about your wishes and those of your loved one.
- **Hospice** can provide multiple forms of support to the patient, caregiver, and family during the end stage of disease. To learn more, visit hospicefoundation.org.

Profiles in caregiving

LORNA BOYLE

"There's nothing we can't do—we just have to plan ahead," says Lorna Boyle, caregiver to her husband, Keith. "With idiopathic pulmonary fibrosis, you can't be in a hurry."

Keith, who was diagnosed with IPF in 2017, "is a project person and enjoys a pretty good quality of life," Lorna says. With a little creative thinking, he's able to stay active. For example, Lorna stands by and hands Keith tools so he won't have to bend and stretch during DIY projects. And when the two take a walk, Keith stops at each fire hydrant to do his breathing exercises while Lorna keeps moving and circles back to him.



The Boyles participate in four support groups and take full advantage of Pulmonary Fibrosis Foundation resources. "Attending the 2019 PFF Summit was one of the best things that ever happened to us," says Lorna, now a PFF volunteer. "Most people have never heard of IPF, so it meant a lot to meet so many couples living an identical life."

Lorna regularly has lunch with friends, participates in fitness classes, and gets her nails done. "At the beginning, I felt selfish if I wasn't with Keith all the time," she says. "But I realized that to be the best caregiver, you have to take care of yourself first. And the time we spend apart gives us so much to talk about when we're together."

LORNA'S TOP TIP: There will be times when you and your loved one will get frustrated with each other. Keith and I have a code word: 'Honey.' That's the signal for us to step back and count to 10.

RESOURCES

For more information on effective caregiving, visit:

[caregiver.org](https://www.caregiver.org)—practical caregiving resources, including short videos and quick reads on topics ranging from transfer skills to nutrition to self-care

[caregiveraction.org](https://www.caregiveraction.org)—education, peer support, and resources for family caregivers, including a caregiver toolbox, chat forums, and video resource center

[caringinfo.org](https://www.caringinfo.org)—resources to help patients and families make informed decisions about care and services before a crisis

[nextstepincare.org](https://www.nextstepincare.org)—guides for helping caregivers and healthcare providers work together to plan and implement transitions for seriously ill patients

[eldercare.acl.gov](https://www.eldercare.acl.gov)—the U.S. Administration on Aging’s resource for connecting with services for older adults and their families

[theconversationproject.org](https://www.theconversationproject.org)—downloadable guides for starting conversations about end-of-life care wishes, choosing and becoming a healthcare proxy, talking to healthcare teams, and more

[getpalliativecare.org](https://www.getpalliativecare.org)—resources for managing the physical and emotional aspects of living with serious illness and locating palliative care in your area

[polst.org](https://www.polst.org)—information on creating physicians’ orders for life-sustaining treatment that apply to all healthcare providers a patient may see

[archrespite.org](https://www.archrespite.org)—resources to help families locate respite and crisis care services in their communities

ACKNOWLEDGMENTS

The PFF gratefully acknowledges the organizations on the left, and these additional sources for information contained in this booklet:

AARP

American Lung Association

Cancer Support Community

Mayo Clinic

National Hospice and Palliative Care Organization

Ofev.com

U.S. Department of Health and Human Services,
Office of Women’s Health

VerywellMind

STILL HAVE QUESTIONS?

Contact the PFF Help Center at
844.TalkPFF (844.825.5733) or
help@pulmonaryfibrosis.org



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