

# The Caregiver Journey: A Guide for IPF



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# **The Caregiver Journey: A Guide for IPF**

**This guide is intended to help IPF caregivers navigate the course of the disease and anticipate challenges that may be encountered along the way. The caregiver journey can be a rough road to travel at times, however, the right tools and support can help pave the way for a positive caregiving experience.**

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## The Caregiver Journey

People with Idiopathic Pulmonary Fibrosis (IPF) and their caregivers can play an active role in disease management. Participation in the treatment plan can help patients, their caregivers and other family members achieve the best quality of life possible and the best results for the patient. This workbook will focus on how caregivers can best help their loved ones with IPF and still maintain their own health and satisfaction with life. We call it caring for the caregiver, **the caregiver journey**.

## What Do We Mean by Caregiver?

Caregivers are people who care for and about, support and assist patients. There is no rule for who can be a caregiver; caregivers may be spouses, life partners, other family members or friends. Caregivers may or may not live in the same home as the patient. Some patients have multiple caregivers who have different roles. Regardless, caregivers provide an important role in helping the person with IPF throughout the course of the disease.

## First Things First

When someone you love is diagnosed with a chronic, progressive or potentially life-limiting condition, it can be an overwhelming and scary time. To meet the care needs of your loved one, additional resources may be necessary.

**Taking time off work:** Sometimes it is difficult to know when to take time off work to be available to care for your loved one. Members of the health care team can talk to you about the benefits of the Family Medical Leave Act (FMLA) and how this might apply to your individual situation.

**Durable medical equipment and supplies:** Oxygen, wheelchairs, walkers and toilet seat risers are all examples of equipment that can be acquired to help with care at home. Members of the health care team can help you sort out what equipment and supplies are needed and how to best access those resources. Companies called durable medical equipment (DME) companies often provide these supplies.

**Home care:** Talk to a member of the health care team about whether you qualify for home care services. Members of the health care team are available to help you review your insurance benefits.

# You Are Not Alone

As you begin your journey as a caregiver, it is important for you to know that you are not alone. While every caregiving situation is unique, many caregivers share similar experiences and face many of the same challenges. Know that resources are available to help you navigate your new role. Managing the daily routine and caring for your loved one can be unpredictable and frustrating, but there are several modes of support available to help.

## Support Team

Building a support team for your patient loved one — and for yourself — is critical. Members of your support team could include many different people. Take a minute and write the names of some supporters that you can call upon when life is overwhelming, when you need a break, when you just need to vent or when you need guidance and help. This list may also include people who can take on the caregiver role when you need a break.

EXAMPLES	MY SUPPORT TEAM
Doctor or health care provider	
Social worker	
Nurse	
Clergy or church family	
Family members	
Friends	
Community resources	
Other caregivers	
Home health or paid caregivers	

Also see “Tools for You Caregiver Journey,” where you can list more of your support team, page 23.



## **Support Groups**

Support groups can be an excellent source of support for people with IPF and for their caregivers. The opportunity to talk with others facing similar challenges can be very comforting for some people. Receiving education about IPF, therapeutic options and ongoing research are just a few benefits of support groups. There are online and live support groups available. Some offer support specifically for caregivers; other are condition-specific.

Check out support groups at [Njhealth.org](http://Njhealth.org), search support groups.

## **Forming Partnerships with Your Health Care Providers**

The partnerships that you and your loved one have with health care providers are an essential element of the caregiving journey. Strong partnerships can result in both the patient and caregiver feeling more informed and educated about the condition, about treatment options and what to expect if the disease progresses. Remember, it is never too early to ask difficult questions.

Also see “Tools for Your Caregiver Journey,” where you can list the health care team, page 24

# Taking Care of Yourself

## Self-Care

Caregivers often neglect their own needs and forget to take time for themselves. Taking care of yourself is one of the most important ways that you can help your loved one. You can't give good care to your loved one if you don't take care of yourself. Studies have shown us that caregivers are very vulnerable to developing their own physical and mental health problems, so please spend a little time each day taking care of yourself. We know that it can sometimes be difficult to leave your loved one, but even a couple of 15- to 30-minute chunks of time throughout the day can relieve stress, reduce tension and leave you re-energized. Do some things for yourself. You are not being selfish; by staying healthy, you are helping your loved one.

Use the space below to identify activities (outside of your caregiving role) that nurture your soul, bring you joy and introduce calm into your life.

SELF -CARE ACTIVITIES I ENJOY	
E.g., Gardening, going to the park, getting coffee	

From the activities listed above, try to identify one activity for each of the following timeframes. Add these activities to the calendar and commit to at least three self-care activities per week. You may not be able to enjoy a daylong activity each week, but see if you can fit this into your calendar sometime.

SELF-CARE ACTIVITY I CAN COMMIT TO THIS WEEK	
30 minutes	
1 hour	
Daylong	

Also see "Tools for You Caregiver Journey," where you can list more Self-Care Activities, page 25.





## Communicating Your Needs

It is important to develop strategies to communicate your needs to your support team and your loved one. Below are some tips for caregiver communication.

- Establish a consistent time for self-care activities.
- Involve your loved one (to the extent that he or she is able) in the establishment of a weekly schedule, and make the schedule visible.
- Reassure your loved one that he or she will have the care needed in your absence.

## Coping with Stress & Burnout

All caregivers experience stress and burnout. It can be challenging to find healthy ways to cope with the mood swings of the person you are caring for. Unanticipated challenges that arise can create stress and frustration. Below are some symptoms of stress. Check ✓ those that you have experienced in recent days. If you have checked two or more, this may be a sign that you are experiencing caregiver burnout. Please talk to a health care provider or a member of your support team to get the guidance and support you need.

- |  |  |
|--|--|
| <input type="checkbox"/> Low energy                | <input type="checkbox"/> Headaches                     |
| <input type="checkbox"/> Irritability or moodiness | <input type="checkbox"/> Upset stomach                 |
| <input type="checkbox"/> Inability to sleep        | <input type="checkbox"/> Aches, pains or tense muscles |

## Unanticipated Joy

Adjusting to the diagnosis of a life-limiting or chronic condition can be challenging, but it does not have to be all negative. Shifting priorities may allow you to plan that trip you have been wanting to take or visit the friend you have not seen for years. Give yourself permission to enjoy time with friends, family and one another. Dedicated time with your loved one may strengthen your bond and enhance your relationship.

## Setting Realistic Goals and Planning

Managing the day-to-day tasks that may be needed to care for a person with a chronic health condition can be challenging. To juggle the tasks that need to be accomplished, you will need to set realistic goals to ensure that you are not taking on too much.

Plan your day or week. Make sure to plan time for yourself.

PLANNING YOUR WEEK						
MON	TUE	WED	THU	FRI	SAT	SUN
Dr. appt Walk	Check medicine Visit with friend	Grocery shopping Walk	DME Co appt	Outing	Daughter bringing lunch	Faith service

Also see “Tools for Your Caregiver Journey,” for a monthly and weekly calendar. page 26 and 27.



## An Action Plan for IPF

Sometimes it is hard to know when your loved one's symptoms change or worsen. Identifying and treating symptoms early is important. The caregiver is often the first person to identify a change or increase in symptoms. Talk with your loved one, health care team and family members about the action plan for increased symptoms.

Also see "Tools for Your Caregiver Journey," for a sample action plan, page 28.

## Advanced Care Planning

Adequate planning in advance of a serious illness or medical diagnosis helps people feel prepared when the unexpected occurs. All healthy adults are encouraged to talk with their health care providers, family members and loved ones about what their wishes would be if faced with a serious medical condition. After these important conversations are held, a person's wishes can be documented in a Living Will and/or Durable Power of Attorney for Health Care.

## Quality Care for End of Life

Through caring conversations and advanced care planning, caregivers will feel better equipped to make health care decisions consistent with a person's wishes if the loved one is unable to make the decisions when the end of life approaches. In addition, palliative care and hospice programs are available to provide valuable services to the person with IPF and family members when the time for that level of care arrives.

### **Advanced Care Planning Resources Include:**

- Advanced Care Planning Med Facts and video
- Distinguishing Palliative Care from Hospice Care
- Palliative Care Med Facts
- Bereavement Support
- Living Will vs. a Will, Five Wishes
- Colorado MOST form

# Transitions and Touch Points in Time for the Caregiver Journey



## What to Expect

Caring for a person who has been diagnosed with IPF presents unique challenges. This section is designed to help inform the caregiver about what to expect as the disease progresses. Thinking of IPF as “Transitions and Touch Points in Time” can help caregivers prioritize their needs and keep them from feeling overwhelmed.

## Touch Points in Time

- Recently diagnosed
- Needing oxygen with activity, but not at rest
- Needing oxygen 24 hours a day, with activity, at rest and during sleep
- Advanced oxygen needs (needing high-flow oxygen or when a lightweight, portable delivery system is unable to meet a patient’s needs). Below, we describe each of these Touch Points — what patients might experience and how caregivers can be most effective.



# TOUCH POINT #1

## Recently diagnosed with Idiopathic Pulmonary Fibrosis



### How can the caregiver help?

- Empower yourself by learning about IPF with your loved one.
  - Resources include:
    - ◆ Njhealth.org/ipf
    - ◆ Pulmonaryfibrosis.org
- Attend health care appointments to be a second set of ears.
- Discuss and write down questions to ask the health care provider.
  - See the list on page 16 for examples of questions.
- Help keep a record of care.
  - See the calendars under “Tools for Your Caregiver Journey,” page 26 and 27.
- Help keep track of medications.
- Empower yourself by learning about health care insurance and Family Medical Leave Act (FMLA).
- Encourage your loved one with IPF to live a full life, including regular exercise, healthy eating, rest and support from others.
- Keep a good supply of waterless soap around the house and in a to-go bag.
- Consider attending a support group, either alone or with your loved one.
- Build your own support team consisting of family, friends, religious groups and/or other caregivers.
  - See “My Support Team” under “Tools for Your Caregiver Journey,” page 23.
- Remember to take care of yourself. Having a loved one with a serious illness can lead people to forget about themselves and their own health. You will not be a good caregiver if you are physically ill or emotionally unwell. Avoid getting burned out by spending some time doing things you enjoy.
  - See “Self-Care Activities I Can Commit to Each Week” under “Tools for Your Caregiver Journey,” page 25.

Remember to live a full life, including regular exercise, healthy eating, rest and support from others.

# TOUCH POINT #1

## Recently diagnosed with Idiopathic Pulmonary Fibrosis



### How might a caregiver be affected?

You may experience a range of emotions when your loved one is diagnosed; these could include denial, fear, stress, anger/frustration, grief or depression. It is important to know that your loved one may not experience the same emotions as you, or he or she may not experience emotions at the same time.

- **Denial:** It may be hard to believe or accept that your loved one has IPF. Experiencing denial for a short period of time is natural; however, longer-term denial is unhealthy and may affect your loved one and delay the initiation of appropriate therapy.
- **Fear:** Fear of the unknown is common. Not knowing how IPF will behave over time is unsettling. Try to focus on the here and now, rather than the what-ifs.
- **Stress:** Not knowing how to help your loved one with IPF can lead to stress. Try to find activities to relieve your stress. Planning for the future can help alleviate stress.
- **Anger/frustration:** It is normal to feel anger and/or frustration at IPF when a loved one is diagnosed. Try to work through it, but realize you may need support. Use your support network and talk to your primary care or mental health provider about what you are dealing with.
- **Grief/depression:** You have not lost your loved one. Your loved one and you have a lot of living to do. Focus on today and on what you can do, not what you can't.



# TOUCH POINT #1

## Recently diagnosed with Idiopathic Pulmonary Fibrosis



### What to expect from the person who is recently diagnosed with IPF

- The person with IPF may be entirely asymptomatic; however, it would not be uncommon for him or her to have shortness of breath when exerting, dry cough and/or fatigue.
- Shortness of breath may only be present with extreme exertion (e.g., climbing a hill). Remember, even people without IPF are at least a little short of breath going up two flights of stairs.
- A cough can be frequent and bothersome. It may only occur when the person with IPF talks for long periods of time or with exertion.
- Fatigue is common and challenging to treat. Eating well, exercising and getting plenty of high quality sleep can help.
- The person with IPF who is just diagnosed may experience an array of emotions. He or she may be afraid or angry, anxious or short-tempered.
- Many people with IPF want to know more about the disease. We discourage online searching at random sites, because much of the information is outdated or inaccurate. You can find good information at:
  - [Njhealth.org/ipf](https://www.njhealth.org/ipf)
  - [Pulmonaryfibrosis.org](https://www.pulmonaryfibrosis.org)



# TOUCH POINT #1

## Recently diagnosed with Idiopathic Pulmonary Fibrosis



### Questions to ask your loved one's health care provider

- What treatments are available to my loved one with IPF now?
- How will those treatments affect my loved one's quality of life?
- What should I expect as disease progresses in a loved one with IPF?
- Are there any support groups available for me to connect with fellow caregivers?
- Are there good websites that provide helpful, reliable information?
- Does my loved one with IPF need any vaccines?
- Does my loved one with IPF have or need treatment for acid reflux?
- Does my loved one with IPF have pulmonary hypertension?  
Should s/he get tested?
- Does my loved one with IPF have obstructive sleep apnea?  
Should s/he be tested?
- What other questions do you have?

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## TOUCH POINT #2

### Needing oxygen with activity, but not at rest



#### How can the caregiver help?

- Continue to be a second set of ears with the health care provider, and now with the durable medical equipment (DME) company also. This is a new company you will both need to work with.
- Continue to discuss and write down questions.
- Learn the ins and outs of the new medical equipment. Examples include: oxygen systems, portable oxygen systems and pulse oximetry.
- Read the book *Adventures of an Oxy-Phile* by Dr. Thomas Petty.
- Encourage the person with IPF to live a full life, including regular exercise, healthy eating, rest and support from others. Breathing techniques can be helpful with exercise.
- Remember to take care of yourself.
  - See “My Support Team” under “Tools for Your Caregiver Journey,” page 23



#### What to expect from the person with IPF using oxygen with exercise

- The person with IPF is short of breath with exertion or activity. Oxygen usually helps decrease shortness of breath, fatigue and even cough in many patients. But it is important to know that oxygen does not totally take away shortness of breath.
- Coughs can be frequent and bothersome. A cough may only occur when the person with IPF talks for long periods of time or with exertion.
- Fatigue is not uncommon at this stage and can be challenging to treat. Eating well, exercising and getting plenty of high quality sleep can help.
- Being prescribed oxygen for use during the day is perceived by many people with IPF as a major step in the wrong direction. But oxygen is not a death sentence! Even so, some people with IPF feel self-conscious using their oxygen in public. This is natural and usually short-lived.

# TOUCH POINT #2

## Needing oxygen with activity, but not at rest



### Questions to ask your loved one's health care provider

- How can my loved one be active when s/he has to carry oxygen around?
- Does staying active actually extend my patient loved one's life, or does it just improve quality of life?
- What resources are available to help my loved one be active with oxygen? Can s/he travel with oxygen?
- Does s/he have the freedom to adjust flow rates based on how s/he is feeling, or is s/he bound to the prescribed flow rate?
- Does s/he need to be extra careful when exercising when using oxygen, or is it based on what s/he can tolerate?
- Do you recommend formal pulmonary rehabilitation and/or self-initiated physical activity?
- Will you monitor her/his oxygen needs at clinic visits? If so, how?
- Are her/his vaccinations up to date?
- What is transtracheal oxygen? Is there a transtracheal oxygen program nearby? Is my loved one a candidate for the procedure?
- Is lung transplantation an option? What do we need to consider?
- What other questions do you have?

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## TOUCH POINT #3

### Needing oxygen 24 hours a day, with activity, at rest and during sleep



#### How can the caregiver help?

- Learn the ins and outs of oxygen systems for use at home, when away from home and when traveling.
- Continue to be a second set of ears with the durable medical equipment (DME) company as the oxygen needs change.
- Continue to discuss and write down questions.
- Encourage the person with IPF to live a full life, including social interactions, regular exercise, healthy eating, rest and support from others.
- If you haven't yet, get the book *Adventures of an Oxy-Phile* by Dr. Thomas Petty.
- Remember to take care of yourself.
  - See "Self-Care Activities I Can Commit to Each Week" under "Tools for Your Caregiver Journey," page 25

#### What to expect from the person with IPF needing oxygen 24 hours a day

- The person with IPF is short of breath with exertion or activity. Even though s/he needs oxygen at rest, s/he will not be short of breath at rest.
- A cough can be frequent and bothersome. It may only occur when the person with IPF talks for long periods of time or with exertion.
- Fatigue is common at this stage and can be challenging to treat. Eating well, exercising and getting plenty of high quality sleep can help. Napping is okay and encouraged.
- Being prescribed oxygen for use 24 hours per day is perceived by many people with IPF as yet another major step in the wrong direction. But, even 24/7, oxygen is not a death sentence! Nonetheless, people with IPF may feel afraid, anxious or depressed and be short-tempered.

# TOUCH POINT #3

Needing oxygen 24 hours a day, with activity, at rest and during sleep



## Questions to ask your loved one's health care provider

- Does my patient loved one need to be careful about physical activity now?
- Is s/he a candidate for a lung transplant? If so, what do we do?
- Are her/his vaccinations up to date?
- Should s/he enroll or re-enroll in pulmonary rehabilitation?
- Does my loved one have pulmonary hypertension?
- What other questions do you have?

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## **TOUCH POINT #4** Advanced oxygen needs (needing high-flow oxygen or when a lightweight, portable delivery system is unable to meet a person with IPF's needs)

### **How can the caregiver help?**

- Learn the ins and outs of the high-flow oxygen system at home, when away from home and when traveling. Calculate how long the portable oxygen system will last when away from home.
- Continue to be a second set of ears with the durable medical equipment (DME) company as the oxygen needs change.
- Continue to discuss and write down questions.
- Encourage the person with IPF to live a full life, including social interactions, regular exercise, healthy eating, rest and support from others.
- Remember to take care of yourself. Consider respite care. Consider palliative care and/or hospice care as indicated.
  - See "My Support Team" under "Tools for Your Caregiver Journey," page 23 and 25.

### **What to expect from the person with IPF and advanced oxygen needs**

- The person with IPF is short of breath with exertion or activity. Even though s/he needs oxygen at rest, s/he will not usually be short of breath at rest.
- A cough can be frequent and bothersome. It may only occur when the person with IPF talks for long periods of time or during exertion.
- Fatigue is common and can be challenging to treat. Eating well, exercising and getting plenty of high quality sleep can help. Napping is okay and encouraged.
- High-flow oxygen cannot be delivered by portable oxygen concentrators, so many people with IPF feel even more constrained. Remember, even high-flow oxygen is not a death sentence! Nonetheless, people with IPF may feel afraid, anxious or depressed and be short-tempered with this new stage. They are at risk for social isolation and mood disturbance.

# TOUCH POINT #4 Advanced oxygen needs (needing high-flow oxygen or when a lightweight, portable delivery system is unable to meet a person with IPF's needs)

## Questions to ask your loved one's health care provider

- What is the normal life expectancy at this point?
- What palliative care resources are available?
- What does the end look like?
- Can you guarantee that my loved one will not suffer?
- What other questions do you have?

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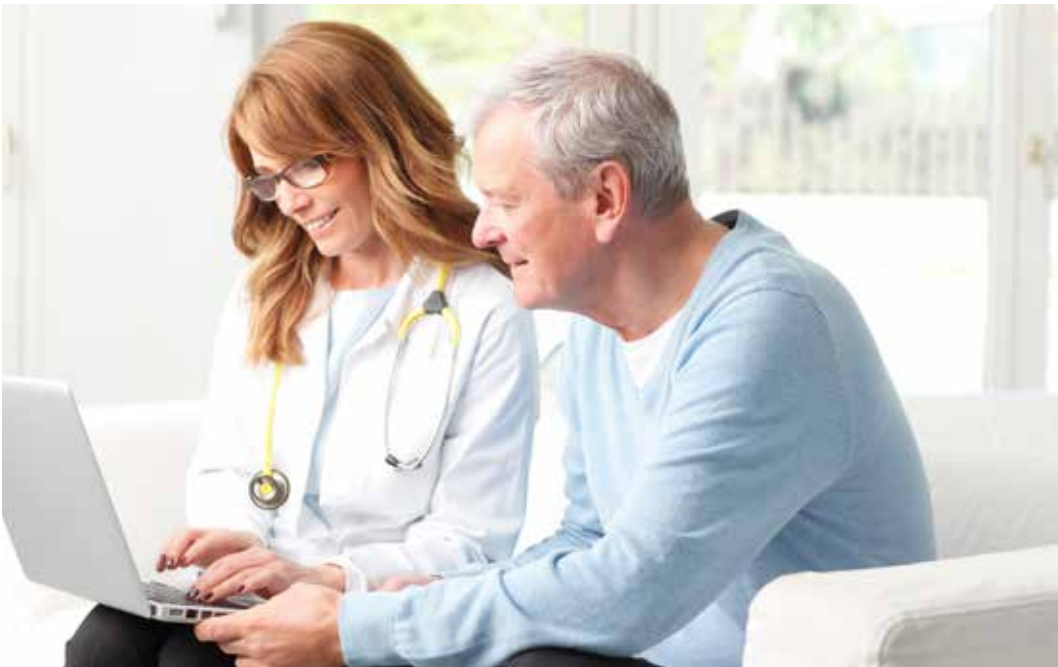
Remember, caregivers may live in the home or out of the home. Caregivers may be a family members or friends. Caregivers play an important role in helping the person with IPF at each touch point in time during the journey.



# TOOLS FOR YOUR CAREGIVER JOURNEY



MY SUPPORT TEAM		
Name	Phone/Email	Comments



# TOOLS FOR YOUR CAREGIVER JOURNEY



<b>PARTNERSHIP WITH HEALTH CARE PROVIDERS</b>	
Doctor Name	Phone #
Address	Phone #
Pharmacy Name	Phone #
Address	
DME Name	Phone #
Address	
Home Care Agency Name	Phone #
Address	
Pharmacy Name	Phone #
Address	
Dentist Name	Phone #
Address	



# TOOLS FOR YOUR CAREGIVER JOURNEY



SELF-CARE ACTIVITIES I CAN COMMIT TO EACH WEEK	
30 minutes	
1 hour	
1 day	

# TOOLS FOR YOUR CAREGIVER JOURNEY



PLANNING YOUR MONTH						
MON	TUES	WED	THURS	FRI	SAT	SUN

# TOOLS FOR YOUR CAREGIVER JOURNEY



PLANNING YOUR WEEK						
MON	TUES	WED	THURS	FRI	SAT	SUN



## **ACTION PLAN FOR IPF** **When to Contact your Health Care Provider**

If you are having increased shortness of breath or chest pain, call 911. An ambulance can take you to the nearest emergency room.

If you are having any of the symptoms below please contact your doctor.

The symptoms include:

- You are more short of breath than usual with rest or activity,
- You have increased oxygen requirements,
- You are coughing up yellow, green, brown or blood tinged sputum or
- You have fevers, chills, nausea or vomiting.

Please call if you have any concerns about how you are feeling or develop new symptoms.

**My Doctor's Name & Phone #** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_











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[njhealth.org](http://njhealth.org)



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