



The World Health Organization estimates that **8% of the global population is dependent on others for care.**

About 44 million Americans provide **37 billion hours of unpaid, “informal” care** each year.

Family caregivers provide 75% of caregiving support in the US. In fact, most of us, at some point in our lives, provide unpaid caregiving assistance to our families, friends, or neighbors.

Source: Family Caregiver Alliance



Identifying as a Caregiver

A caregiver is anyone who provides help to another person in need. However, family members who are actively caring for a loved one don't often self-identify as a “caregiver.” Recognizing this role can help family caregivers, together with non-family member caregivers, receive the support they need.



What does a Caregiver do?

What doesn't a caregiver do? A caregiver does whatever is needed for the patient. Being a lung transplant caregiver, before and after transplant, is a big responsibility. Sometimes, depending on the patient, the need is so great that more than one caregiver may be necessary to share the responsibility, especially during the first few months after transplant. Lung transplant caregivers often are considered long-term caregivers, since lung transplant recipients frequently need care for weeks to months after transplant.



How to Prepare Yourself to Become a Lung Transplant Caregiver

Caregivers need to identify themselves specifically as lung transplant caregivers as they start to search for resources that can help them navigate this new role. Caregivers often receive information from the transplant center about how to be successful in the role. In fact, many transplant centers require caregivers to accompany patients on several pre-transplant appointments, and they often provide detailed training before recipients go home after transplant.





First Steps for New Caregivers

- Always identify yourself as a caregiver.
- Help the patient advocate for themselves to ensure an accurate diagnosis and don't hesitate to get a second opinion if you feel it is necessary.
- Identify specific skills you might need to acquire (for example, educate yourself on oxygen usage).
- Understand the patient's financial responsibilities and healthcare wishes.
- Help patients complete legal paperwork (Power of Attorney, Advance Directives, etc.).
- Bring family and friends together to discuss the patient's care and create a caregiver team, if possible.
- Identify resources both in your community and otherwise before you need them (see list below).
- Find support for both you and the patient (example, Lung Transplant Foundation Joseph J. Carter Mentorship Program).
- You don't have to do this alone.



Caregiving Post Transplant

- Make sure medications are taken in the right doses at the right times.
- Help record all information that the lung transplant team requested.
- Drive the recipient to and from follow-up appointments.
- Attend appointments.
- Look for signs of unusual behavior and symptoms. Contact the transplant team if anything seems wrong.
- Shop for food and prepare meals.
- Run errands, fill prescriptions, and do chores around the house.
- Provide support, encouragement, and entertainment.
- Keep family and friends informed of the recipient's progress, needs, and wishes.

Source: UPMC Lung Transplant



10 Tips for Family Caregivers

1. Seek support from other caregivers. You are not alone.
2. Take care of your own health so that you can be strong enough to care for your loved one.
3. Accept offers of help and suggest specific things people can do to help.
4. Learn how to communicate effectively with doctors.
5. Take respite breaks often.
6. Look for signs of depression and don't delay getting professional help when you need it.
7. Be open to new technologies that can help you care for your loved one.
8. Organize medical information so it's up to date and easy to find.
9. Make sure legal documents are in order.
10. Give yourself credit for doing the best you can for a loved one in one of the toughest jobs there is!

Source: Caregiver Action Network



Caring for Caregivers

Being a caregiver creates stress and, at times, may feel overwhelming. Caregivers will experience challenges during the lung transplant process which can significantly impact their day-to-day quality of life. It's essential for all caregivers and patients alike to know the signs of caregiver overload, to recognize when demands exceed resources, and how to act upon these signs.

Signs of Caregiver overload:

- Signs of anxiety, depression and feelings of powerlessness.
- Emotions such as guilt, fear, and death anxiety are not uncommon.
- Physical symptoms including fatigue and difficulty sleeping.
- Financial issues related to caregiving can build up and will need to be addressed.
- Be prepared to experience life management conflicts such as the inability to navigate additional responsibilities of caregiving with employment, family requirements, and possibly even having to put your own life on hold.



Self Care is Essential for Caregivers

Self-care is about being deliberate in taking time for yourself for the health of your mind, body, and soul. Self-care is NOT selfish. It is about replenishing your spirit in different ways. Take care of yourself first. Here are some ways to keep yourself mentally and physically prepared for this role:

- Put time on your calendar to put your own health and well-being first.
- Exercise daily, even if it's just a few minutes for a short walk. This will revitalize you physically and mentally.
- Maintain a healthy diet. Choose whole foods instead of fast foods. Keep healthy snacks available at home and when on-the-go.
- Get the rest you need! A good night's sleep is one of the best ways to take care of yourself.
- Listen to calming music or apps in waiting rooms, while driving, or as you can find time. Some find this to be a lifesaver in getting through stressful times.
- Make time for an activity you enjoy.
- Ask for help before you need it. Friends and family are eager to help and they may not know what you need. Ask for help with preparing meals, cleaning the house, yard work or chores. Then...accept it!
- Watch for signs of stress or depression. Don't wait to reach out for the help you may need.
- Help the person you care for to develop independence. The more you do for them, the less they'll do for themselves. This can be a gift to both of you.
- Take pride in being a caregiver and feel good about what you do. Know that you are appreciated

"There are only four kinds of people in the world: Those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need a caregiver." —Rosalyn Carter





Where to Turn for Support

There are many resources for caregivers. Most transplant centers have licensed clinical psychologists and social workers who specialize in supporting families facing transplant.

Look for local resources that can provide assistance for things such as transportation for appointments, home delivered meals, oxygen suppliers, support groups, and even house cleaning. If possible, create a 'backup list' of family and friends who are willing to assist if/when things become overwhelming.



Try reading books by people who have experienced what you are going through. Here are two:

"Take A Breath, A Transplant Journey"
by Karen A. Kelly, M.D.

"You Want Me to What?" by Donna Mogan, PhD



Websites that offer countless resources for caregivers:

Caregiver Action Network:

caregiveraction.org

Family Caregiver Alliance:

www.caregiver.org/connecting-caregivers

TRIO:

www.trioweb.org/links/item/professional-organizations-2.html

The Gift of Life Family House: Caregiver Lifeline Program- www.giftoflifefamilyhouse.org

Caring Bridge:

www.caringbridge.org/category/resources/caregiver-support

National Caregivers Library:

www.caregiverslibrary.org

Lotsa Helping Hands:

lotsahelpinghands.com

Finding yourself in a position as a primary caregiver for a lung transplant recipient is challenging and complex. It can often feel overwhelming and isolating. While each journey through lung transplant is individualized, those who have experienced it share a common thread. There are people and organizations to turn to for help. Take advantage of these resources to help navigate through this difficult journey.

"Caregivers are often the behind the scenes heroes."- Dr. Karen A. Kelly

