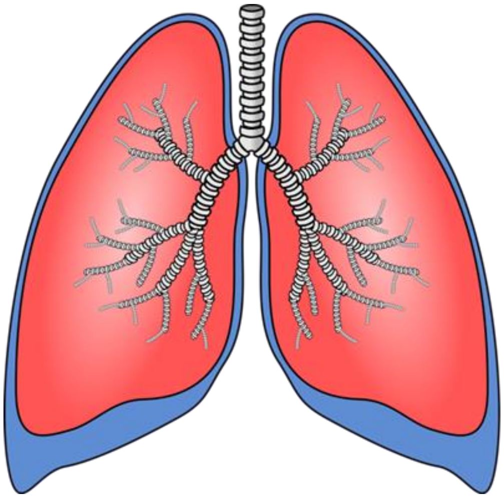

Lung Transplant Caregivers

UCSF Medical Center
Lung Transplant

Introduction

Planning for lung transplant involves many tests, frequent appointments, and ongoing communication with your nurse coordinator. In addition to the UCSF team, you will need your own team – ***your caregiver team*****.** These are the friends or family who will help take care of you after you are discharged from the hospital following your lung transplant.

What Caregivers Do

Your caregivers provide you with physical, emotional and practical help after transplant. They remain with you full-time to assist you for at least six weeks after your discharge from the hospital. You and your caregiver(s) will need to stay locally, which means no more than 30 minutes from UCSF (with no bridges between you and UCSF). This is not only for your convenience due to the multiple follow-up appointments, but also to make sure you can quickly get back to UCSF Hospital if there is an emergency.

Because caregivers are so critically important to your post-transplant outcome, we cannot list you for transplant until you have identified two caregivers who can assist you after transplant**.**

We now will review the role of the caregiver, before, during and after transplant.

Choosing Your Caregivers

Your caregiver can be any person in your life with whom have a strong relationship. It can be a family member, but it can also be a close friend or friends. Ideally, it should be someone you feel comfortable spending a lot of time with, because you will be together 24/7 for six weeks after your discharge!

We do not require or expect that your caregivers have a medical or nursing background, just that they be willing to learn and are committed to following our instructions.

Here are some things to think about when choosing caregivers:

1) Can they relocate on short notice? You can plan to be in the hospital for about two weeks after transplant, so there will be some time for them to prepare. Your caregiver will need to come to the hospital a few days prior to your discharge to be available for teaching sessions.

2) If they are working, can they afford to take time off? If they are relatives, under certain circumstances, they may be able to take paid time off.
3) Do they have other responsibilities at home? If your caregiver is already caring for others (people and/or pets), can someone else step in to help them?
4) Do they have any health limitations?
5) Are they generally reliable and organized? Will they be able to communicate with the UCSF team on your behalf about any issues you are having?

How Many Caregivers Can I Have?

You can choose up to three caregivers who will help you post-transplant. Some people have found that it is easier to split up the caregiver duties into segments of two or three weeks among different people.

If this is your plan, please make sure your caregivers have a way to communicate with each other and have this worked out prior to transplant. This can include text messages, an e-mail group, or a website like Caring Bridge. If there are multiple caregivers, they should all plan to attend the education sessions. We can set this up on Zoom if they are out of the area.

Can I Hire Caregivers?

Unfortunately, this is not an option for our transplant patients. We ask that your caregiver have a personal relationship with you, and that they understand and sign our caregiver agreement. There is no guarantee that paid caregivers will be available to you when you need them, and they will not have the same kind of commitment to take care of you.

The Primary Caregiver

This is the main person who will help you after transplant. Even if you have multiple caregivers, we ask that you identify <u>one</u> as our point of contact. This person will also make sure that the plan is going smoothly.

You will not be in a position to figure out things like lodging or transportation back and forth to UCSF and will need to rely on your caregiver to do this.

Some primary caregivers plan to do all the care with the secondary as a "just in case person". We strongly advise that they plan for some respite, and have a support person of their own.

The Secondary Caregiver

The secondary caregiver is a vital part of the plan, and one important role is to provide respite for the primary caregiver. If the primary caregiver gets ill or is injured, then the secondary caregiver needs to be ready to step in for the entire six weeks.

What Are All the Different Options?

1) The primary caregiver plans on covering the entire six weeks, with the secondary caregiver available as needed
2) The primary caregiver and secondary caregiver split up the time in segments
3) Up to three caregivers are involved, with the primary caregiver acting as coordinator
4) If you are staying in a hotel or renting an apartment, you will have more flexibility in your arrangements. If you are staying at Koz House, they will only let you switch caregivers every two weeks.

Prior to Transplant Listing

Once you have identified your caregivers, they should go to our education website (LungTransplantEducation.UCSF.edu) and watch the Patient Education - Part I video and at least <u>some</u> of the Patient & Caregiver Experience videos.

In particular, the Caregiver Experience videos will give them a clear picture of what it's like to care for someone during the recovery period. We strongly suggest that people educate themselves as much as possible before making this commitment.

Once your caregivers have watched the videos (or read the handouts), the social worker will arrange to connect with each of them to provide education, answer questions and go over the caregiver agreement.

We encourage you to have your caregivers come to appointments with you during this process if possible. This is a good way for them to learn about your condition and get to know our transplant team.

Getting a Ride to the Hospital

You will need to identify a person (or people) who can give you a ride on short notice to UCSF when we call you in for transplant. This does not have to be your caregiver, but it should be someone local who could stay with you until you are admitted, and someone who could take you home if you are not admitted or if the donor offer doesn't work out.

During the Hospital Stay

Your caregivers do not need to be with you the whole time you are in the hospital. This can be a good time for them to take care of things at home or work before your hospital discharge. However, your caregivers should plan to arrive at UCSF a few days before your anticipated release date. If your caregivers are from out of town, they will need to arrange their own lodging.

They will need to be present for discharge teaching and to get needed supplies. We will teach them what they need to know about taking care of a transplant patient, including when and how to call staff if there are concerns. Their part is to be as prepared as they can and to ask questions.

Their tasks will include:

☐ Obtaining post-transplant lodging. Let the social worker know as soon as you have the address.

☐ Notify the social worker if you would like to stay at the Koz House (UCSF guesthouse).

☐ Arranging for a leave of absence from work if necessary

☐ Arranging for care of their children, pets or others if needed

☐ Attending education sessions at UCSF with pharmacists and the post-transplant coordinator, as well as other team members

☐ Watch the post-transplant teaching videos before teaching sessions.

☐ Before the nurse coordinator teaching session, go to lungtransplanteducation.ucsf.edu and watch the video "Lung Transplant Care and Monitoring. "

- ☐ Before the pharmacist teaching session, go to lungtransplanteducation.ucsf.edu and watch the videos “Understanding Your Medication Card” and “Organizing Your Medications Using a Pill Box.”
- ☐ Work with your social worker to get employment or disability paperwork completed for the patient and the caregiver, if needed
- ☐ Confirm the schedule with other caregivers
- ☐ Purchase a medi-wedge 6” pillow (www.mediwedge.com) or bring one from home
- ☐ Purchase or bring from home a bathroom scale, pillbox, blood pressure cuff, pill cutter, and thermometer.

The social worker or case manager will talk with you about discharge transportation.

The Six -Week Local Stay

Once you have been discharged, it can feel like you’re back at UCSF all the time!

There are up to four follow-up appointments each week, and your caregiver will need to accompany you to each visit.

In general, most of our patients are walking and able to take care of themselves after hospitalization, but you will still need help throughout the day.

The caregiver’s tasks will include:

- ☐ Transportation back and forth to UCSF for appointments and testing. The caregiver does not need to drive and can use a ride-share or taxi if necessary
- ☐ Attending all appointments with you
- ☐ Helping keep track of all appointments and testing
- ☐ Food shopping and meal preparation
- ☐ Helping keep track of daily vital signs, like weight and blood pressure

☐ Physical assistance as needed – this can include help in and out of a car, standing by during a shower, or help getting you dressed or to the bathroom

☐ Helping keep track of up to 30 new medications, including oral medications, inhaled medications that need to be mixed, injected medications, finger sticks and insulin (if you are diabetic)

From time-to-time, our patients will need complex care, like tube feeing or wound care. If this is the case, there will be a home health nurse sent to help the caregiver learn how to do this.

We rely on the caregivers to be our eyes and ears and to call us with any questions or concerns, urgent or non-urgent.

Being a caregiver for a lung transplant patient is a true gift as well as a big commitment. Because of this, we want to make sure that transplant caregivers have their own support and the opportunity to rest.

The Transition Home

After your six-week stay, you may be eager to head home or nervous about going home – or both! Each patient's recovery is different, and you may still require help once you are home.

You will not be able to drive until the doctor gives you the "go-ahead" and until this happens, you will need transportation for labs and follow-up visits. Outpatient bronchoscopies are done with sedation, so you will need rides for these procedures, even two years after transplant.

You will continue your recovery for the next several months and will need help on a periodic basis if issues come up, if you live alone or if your caregivers live out of the area. Please talk with your social worker about a transition plan that has built-in support in case you need it.

If The Caregiver Plan Changes

If your caregiver plan changes at any point before or after you are listed for transplant, you must notify your nurse coordinator or your social worker. The social worker is required to meet with any new caregivers in order for you to remain listed.

If you have been listed for a number of months or years, the social worker will check in with you about your caregiver and lodging plan. It is vital that you update us - because without an adequate caregiver plan, you are not eligible for transplant, even if you are already listed.

For the Caregiver…

On behalf of UCSF Lung Transplant – Thank You!

Lung transplant is a partnership between the patient, the team at UCSF and you. We cannot do this life-saving work without your help. We deeply appreciate all that you are doing to support the patient and our team.

If you have questions or concerns, the social worker is here to assist you and we encourage you to reach out to us at (415) 514-6799 or (415) 353-1098.