



# Special Considerations with Caregiving

## In this chapter, you will find:

Cultural, Spiritual, and Religious Considerations with Caregiving _____	1
Caregiving When You Work _____	2
End-of-life and Palliative Care _____	3
Privacy Issues _____	4
Clinical Trials and Research _____	4
Multi-Organ Transplant _____	5
Planning for Emergencies _____	5
Questions to Consider and Ask Your Transplant _____	9
Resources _____	10
References _____	10

## Cultural, Spiritual, and Religious Considerations with Caregiving

### Language considerations

Understanding medical words and specific health ideas can be hard for patients who are not native English speakers. A medical interpreter is trained to accurately communicate healthcare information between a patient and the healthcare team. As a caregiver, you may want to help provide interpretation for your loved one; however, using a medical interpreter can help relieve you from this task. It is required by law that all healthcare organizations who receive federal funding provide language accommodations. You or the patient can request for language accommodations, such as a medical interpreter.

Using a medical interpreter:

- protects patient privacy.
- can be more accurate, especially with medical words and ideas.
- is required in some states or medical centers.

### Cultural expressions of care

Medical care differs by culture. Tell the transplant team about your cultural needs. Also, tell the team if you think cultural differences are affecting the patient.

Culturally (and generationally), patients and caregivers might have different ideas about:

- the need for (or benefit of) the transplant.
- asking other people (especially outside the family) for help.

- who the caregivers should be.
  - family member or non-family member
  - female or male
  - older family member or younger family member
- how the family should work together.
- the importance of independence.
- communication and solving conflict.

If you are worried about your immigration status, you might worry about your ability to care for the patient.

### **Spiritual and religious considerations**

Religion and spirituality are important to many patients and caregivers. Think about how spiritual and religious beliefs impact you, the patient, and the care you provide.

Patients who have a strong feeling of spirituality may have better physical and mental health. Spiritual and religious beliefs can help patients and caregivers cope with the transplant process.

Talk with the patient to understand their:

- spiritual or religious beliefs about life, death, and coping.
- traditions and rituals.
- desire to talk with cultural or religious leaders when making medical decisions.

Tell the transplant team about your and the patient's spiritual or religious needs and preferences. You can also ask if the transplant center has a chaplain or provides religious support.

### Caregiving When You Work

Working while you are a caregiver can be difficult. Find ways to balance both responsibilities:

- Ask the transplant center's social worker to help you make a plan.
  - How might the transplant process affect you, legally and financially<sup>1</sup>?
  - How much time will you need to take off work?
  - How will taking time off work affect you financially?
  - How can you complete caregiving and work responsibilities?
- Talk to the patient and transplant team about returning to work (or increasing your hours).
  - Will the transplant center require a second caregiver, so the patient has full-time care?
  - Are your work plans flexible? (You won't know how long the patient needs care.)
- Ask family and friends to help care for the patient when you are at work.
  - Who can help care for the patient when you have work or personal appointments?
  - Who is available if you need unplanned or last-minute help?

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<sup>1</sup> <https://power2save.org/caregiver-toolkit-chapter-2/>

- Talk with your job.
  - How much time off will you need?
  - What are your employer's expectations?
  - Can you use FMLA<sup>2</sup> for time off?
  - Are there programs that support employees who are caregivers?
- Plan ahead.
  - Update your calendar with the patient's medical appointments and tests.
  - Use websites or apps to help you track appointments, medications<sup>3</sup>, and requests for help<sup>4</sup>.
  - Coordinate appointments when you can.
- Take care of yourself<sup>4</sup>! Working and being a caregiver can be difficult and tiring.

## End-of-life and Palliative Care

Early in the transplant process, talk with the patient about how they want to make end-of-life decisions. These conversations are difficult, but you must know the patient's preferences, so you can advocate for them. Talking early can also reduce stress later in the transplant process.

### Decision-making

At the start of the transplant process, the patient must choose a power of attorney<sup>2</sup>, or a person who will make medical decisions for them.

- Help the patient complete all the paperwork for power of attorney.
- Know where to find copies of all documents.
- Talk with the patient about their end-of-life wishes<sup>5</sup>. Be prepared that the transplant might not go well or that the patient might not live long after the transplant.
- Talk with the patient's family about their wishes.

### Palliative care

The patient might want palliative care. Palliative care is:

- medical care to relieve symptoms and improve quality of life.
- not just for patients who are dying.
- not the same as hospice (medical care for people who will probably die within 6 months).

Learn more about palliative care:

- National Hospice and Palliative Care Organization (NHPCO)<sup>6</sup>
- Choosing Wisely<sup>7</sup>

<sup>2</sup> <https://power2save.org/caregiver-toolkit-chapter-2/>

<sup>3</sup> <https://power2save.org/caregiver-toolkit-chapter-1/>

<sup>4</sup> <https://power2save.org/caregiver-toolkit-chapter-3/>

<sup>5</sup> <https://order.nia.nih.gov/sites/default/files/2018-03/advance-planning-tip-sheet.pdf>

<sup>6</sup> <https://www.nhpco.org/patients-and-caregivers/>

<sup>7</sup> <https://choosingwisely.org/>

- NIH National Institute on Aging, “What are Palliative Care and Hospice Care?”<sup>8</sup>
- NIH National Institute of Nursing Research Palliative Care Resources<sup>9</sup>

Ask your transplant team about a palliative care consultation.

## Coping with loss

Some patients die before or after transplant. Losing a person you love is overwhelming and painful. Remember, there is no right way to grieve.

You might feel grief during the transplant process, even if the patient does not die. You might feel a loss of lifestyle, future plans, or relationships as the patient’s physical health changes.

It’s OK to struggle with grief, and it’s ok to ask for help<sup>10</sup>.

- National Hospice and Palliative Care Organization “Experiencing Grief”<sup>11</sup>
- People might ask how they can help as you grieve. Here are some ideas.<sup>12</sup>

## Privacy Issues

Talk with the patient and transplant team about what health information they will share with you.

Learning sensitive health information about the patient can affect your relationship. The patient might want to keep some information private (substance use, mental health, etc.).

Ask how HIPAA (Health Insurance Portability and Accountability Act of 1996) protects the patient’s health information.

## Clinical Trials and Research

Many transplant centers participate in transplant-related research. Your transplant center might ask you or the patient to participate by:

- completing surveys.
- taking new medication.
- trying new products.

You can decide if you want to participate in research studies, or clinical trials. You never have to participate if you do not want to.

If you or the patient are interested in research studies, ask your transplant team for more information.

- Is the transplant center involved in clinical trials?
- Can patients join the clinical trials?
  - What are the patient requirements (age, medical condition, type of transplant, etc.) to join?

<sup>8</sup> <https://www.nia.nih.gov/health/hospice-and-palliative-care/what-are-palliative-care-and-hospice-care>

<sup>9</sup> <https://www.ninr.nih.gov/newsandinformation/publications/palliative-care-resources>

<sup>10</sup> <https://power2save.org/caregiver-toolkit-chapter-3/>

<sup>11</sup> <https://www.caringinfo.org/planning/grief-and-loss/understanding-grief-and-loss/>

<sup>12</sup> <https://www.caringinfo.org/planning/grief-and-loss/supporting-a-grieving-caregiver/>

- What are the benefits and risks of joining (or not joining) clinical trials?
- Are there other research studies open to patients (not only clinical trials)?
  - What are the patient requirements to join a study?
  - What are the benefits and risks of joining (or not joining) studies?

## Multi-Organ Transplant

Some patients need more than one organ transplant at the same time (multi-organ transplant). If your patient needs multi-organ transplant:

- you will have separate appointments for each organ.
- one organ transplant team will be the primary team.
  - For example, the heart transplant team will probably be the primary team for a patient who needs heart and kidney transplants.
- The primary team will make most decisions during the transplant process.
- The primary team will provide care after the transplant.

Ask your transplant center about their procedures for multi-organ transplants. See Questions to Consider and Ask Your Transplant Center, below.

## Planning for Emergencies

Don't wait for an emergency to start planning! Planning for emergencies can keep you and the patient safe, especially if you are in an area with frequent natural disasters.

Emergencies impact patients who have organ failure, transplant, or a left ventricular assist device (LVAD)<sup>13</sup> in many ways. For example,

- loss of electricity for medical devices,
- limited access to medications,
- dehydration from limited access to clean drinking water,
- extreme heat or cold,
- no access to health care,
- no safe route to the transplant center,
- flooding that causes mold, fungus, or bacteria,
- high winds that cause valley fever, cocci, or pollen, and
- poor air quality from wildfire smoke

### Preparing for an Emergency or Natural Disaster

- Ask your transplant center about their emergency planning procedures.
- When you plan, include your homecare agency, pharmacy, and medical equipment company.
- Tell your power company about the patient and ask for priority service when power returns.

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<sup>13</sup> <https://power2save.org/caregiver-toolkit-chapter-7/>

- Know what medical devices are affected by a power outage or evacuation:
  - oxygen concentrator
  - LVAD
  - continuous positive airway pressure (CPAP) or bilevel positive airway pressure (BiPAP) machine
  - nebulizer
  - ventilator
  - feeding pump
  - inotropes pump
  - IV medication pump
  - *LifeVest* defibrillator
  - vest chest therapy device
  - home dialysis equipment
- Plan for power alternatives, like a generator or portable batteries. (If you use a generator, follow the instructions exactly to prevent carbon monoxide poisoning.)
- Plan where you will stay (family, friend, emergency shelter) if power outages last a long time.
- List the addresses and phone numbers of the closest hospital, fire department, and police station.
- If there is a disaster alert, immediately ask for extra:
  - oxygen tanks,
  - dressing/bandage supplies,
  - medications, and
  - supplies for diabetes.
- Write a list of all medication and medical equipment (make, model, type and supplier).
- Review a basic family emergency plan with all family members. (Remember to plan for pets.)
- Pre-register yourself and the patient with local emergency medical shelters. Ask if you can have a private area in the shelter, because of the patient's increased risk of infection.
- If you have an RV or trailer, plan different housing depending on weather. (A trailer might not be safe in extreme heat or high winds).
- Create an evacuation, or exit, plan before an emergency happens.
- Evacuate immediately when there is a disaster alert.
- Tell your transplant or LVAD center when you get to a safe place. Continue to tell them where you are during a disaster.
- Have First Aid Kits at home and in every car. For a family of 4, the American Red Cross recommends:
  - 2 absorbent compress dressings (5 x 9 inches)
  - 25 adhesive bandages (assorted sizes)
  - 1 adhesive cloth tape (10 yards x 1 inch)
  - 5 antibiotic ointment packets (approximately 1 gram)
  - 5 antiseptic wipe packets

- 2 packets of aspirin (81 mg each)
- 1 emergency blanket
- 1 breathing barrier (with one-way valve)
- 1 instant cold compress
- 2 pair of non-latex gloves
- 2 hydrocortisone ointment packets (approximately 1 gram each)
- 1 3 in. gauze roll (roller) bandage
- 1 roller bandage (4 inches wide)
- 5 3 in. x 3 in. sterile gauze pads
- 5 sterile gauze pads (4 x 4 inches)
- Oral thermometer (non-mercury/non-glass)
- 2 triangular bandages
- Tweezers
- Emergency First Aid guide
- Make an Emergency Kit. FEMA recommends:
  - Water: one gallon per person, per day (3-day supply for evacuation, 2-week supply for home)
  - Food: non-perishable, easy-to-prepare items (3-day supply for evacuation, 2-week supply for home)
  - Flashlight
  - Battery-powered or hand-crank radio (NOAA Weather Radio, if possible)
  - Extra batteries
  - First aid kit (see above for recommended items)
  - Medications (7-day supply) and medical items
  - Multi-purpose tool, like a Swiss Army knife
  - Sanitation and personal hygiene items
  - Copies of personal documents (medication list and pertinent medical information, proof of address, deed/lease to home, passports, birth certificates, insurance policies)
  - Cell phone with charger
  - Family and emergency contact information
  - Extra cash (ATMs might be inoperable)
  - Extra fuel for generator and car
  - Extra house and car keys
  - Towels, plastic sheeting, duct tape, scissors, and work gloves
  - Medical-care items, baby supplies, pet supplies (if needed)

### **Emergency Preparedness Resources**

- Federal Emergency Management Agency (FEMA): 1-800-621-FEMA (3662) or 1-800-462-7585, <https://www.fema.gov/>
- Transitional sheltering assistance: <https://femaevachotels.com/>

- Resources for individuals, businesses, and communities:
  - <https://www.disasterassistance.gov/>
  - Ready.Gov: <https://www.ready.gov/be-informed>
  - Disaster Relief information: <https://www.benefits.gov/categories/Disaster%20Relief>
  - The American Red Cross: <https://www.redcross.org/get-help.html>
  - FDA tips about medical devices and hurricane emergencies: <https://www.fda.gov/medical-devices/emergency-situations-medical-devices/medical-devices-and-hurricane-emergencies>
- Phone apps
  - In Case of Emergency (ICE)
  - FEMA
  - American Red Cross
  - Center for Disease Control
  - National Hurricane Center
  - Flood and water level tracking
  - Earthquake interactive mapping
  - Weather
  - Radio
  - Pharmacy
  - Healthcare patient portal
  - Local community emergency preparedness apps (like JaxReady in Jacksonville, FL)
  - Flashlight

## **Pandemic**

Plan how you will care for the patient (before and after transplant) if there is a pandemic or other large-scale disease outbreak.

- Ask your transplant team how they plan for a pandemic. Ask each program the patient is listed with.
- Ask what tests are required and how to complete them (if the patient is in the evaluation process).
- Tell your transplant coordinator if the patient is sick or hospitalized.
  - The patient has a better chance of staying on the transplant list (pre-transplant).
  - The transplant team can help prevent organ damage or rejection (post-transplant).
- Tell your transplant team if the patient's insurance changes.
- Follow Centers for Disease Control and Prevention (CDC), local, and state guidelines to stay healthy and safe during the pandemic.
- Take care of your physical health:
  - Eat nutritious food and drink water.
  - Be active. Get outside for a change of scenery.
  - Brush your teeth and bathe regularly.



- Take care of your mental health.
  - It's normal to feel anxious, sad, frustrated, disappointed, and angry.
  - Ask for a referral to a mental health provider if these feelings become overwhelming.
  - Always be honest with your support team and the transplant team.
- Ask about hospital visitor policies during the event, as you might not be able to visit the patient as you had planned to do.
  - Hospitals might have a no visitor policy, limited visitor policy, or shorter visiting hours.
  - If you cannot stay at the hospital with the patient, call or video chat as much as you can.
- Ask about your transplant center's Telehealth options. Telehealth allows providers to use a computer, phone, or tablet to see patients safely during a pandemic.

*Adapted from "11 Things You can Do to Get Ready for a Kidney Transplant During COVID-19." End Stage Renal Disease National Coordinating Center (ESRD NCC). Accessed June 15, 2020.*

## **Flu Season**

Flu (influenza) season is usually from October to May every year. The flu spreads easily between people. Flu symptoms can include:

- headache,
- body ache,
- high fever,
- sore throat,
- fatigue, and
- runny nose.

Your transplant team will probably recommend that you and the patient get the flu vaccine. Talk to your doctor and the transplant team about the flu vaccine.

Help your transplant patient stay healthy and safe. In addition to the vaccine:

- wash your hands often,
- don't touch your eyes, nose, and mouth,
- cover your mouth when you cough,
- don't get close to people who are sick, and
- follow good health habits (eat healthy food, drink water, sleep enough, etc.).

## **Questions to Consider and Ask Your Transplant**

- Does the center offer in-person or telephone interpreter services?
- What are the center's requirements for caregivers who also work?
- What are the center's emergency preparedness policies?
- Is the transplant center involved in clinical trials?
  - Can patients join the clinical trials?
  - What are the requirements to join?

- What are the benefits and risks of joining (or not joining)?
- Is the center involved in other research studies (not clinical trials)?
  - Can patients join the studies?
  - What are the requirements to join?
  - What are the benefits and risks of joining (or not joining)?
- What are the procedures for a multi-organ transplant? What organ team will be the primary team?

## Resources

### Advanced Care Planning

- National Institute on Aging, “Advanced Care Planning: Health Care Directives”  
<https://www.nia.nih.gov/health/advance-care-planning-health-care-directives>

### Palliative Care

- National Hospice and Palliative Care Organization (NHPCO): <https://www.nhpco.org/patients-and-caregivers/>
- <https://www.choosingwisely.org/wp-content/uploads/2018/02/Palliative-Care-AAHPM.pdf>
- NIH National Institute on Aging, “What are Palliative Care and Hospice Care?”:  
<https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care>
- NIH National Institute of Nursing Research Palliative Care Resources:  
<https://www.ninr.nih.gov/newsandinformation/publications/palliative-care-resources>
- National Hospice and Palliative Care Organization “Experiencing Grief”:  
[https://www.nhpco.org/wp-content/uploads/2019/04/There\\_is\\_no\\_Wrong\\_or\\_Right\\_Way\\_to\\_Grieve\\_After\\_a\\_Loss.pdf](https://www.nhpco.org/wp-content/uploads/2019/04/There_is_no_Wrong_or_Right_Way_to_Grieve_After_a_Loss.pdf)

### Emergency Preparedness Resources

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- Resources for individuals, businesses, and communities:
  - <https://www.disasterassistance.gov/>
  - Ready.Gov: <https://www.ready.gov/be-informed>
- Disaster Relief information: <https://www.benefits.gov/categories/Disaster%20Relief>
- The American Red Cross: <https://www.redcross.org/get-help.html>
- American Thoracic Society Disaster Related Resources:  
<https://www.thoracic.org/professionals/clinical-resources/disaster-related-resources/>

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