Providing support for the transplant patient

Having a transplant has a huge impact on your life and the lives of your entire support system. This guide offers information on the kind of support transplant patients need and what caregivers can do to help.

Hartford HealthCare

Hartford Hospital

Table of Contents

Waiting for the transplant	1
When you are called for the transplant	1
Your hospital stay	2
After discharge	2
How to help the transplant patient	3
Medication management	3
Activities of daily living	3
Emotional support	4
What patients don't need	4
Tips for caregivers	5
Summary	5
We're here to help	back cover

Waiting for the transplant

Once you are added to the transplant wait list, it's important that you are prepared. One of the first things we ask you to do is choose one or two "care partners" to help prepare for transplant and help with care. These people will also meet with our Transplant Team.

When you are called for the transplant

Things to know:

- You may be called at any time and need to be ready to leave the house within an hour.
- Our transplant coordinator may call from a number you don't recognize, so please be prepared to answer your phone at all times and have your voicemail set up and clear of excess messages. You should return missed calls promptly and tell the Transplant Team if your contact information changes.
- You will need to make arrangements to let your employer know and to have your children, pets, household bills, etc., taken care of while you're in the hospital.
- If you will be driving to the hospital, make sure your vehicle is in working condition, fueled up and ready with directions or a map to Hartford Hospital.
- Have a copy of your medical insurance card, photo ID and prescription/drug coverage card(s) ready to take with you.

Things to consider:

- How will you get to the hospital?
- If you'll be flying, do you have the needed funds set aside?
- If you are going by car, who will be driving?
- Who is your back-up driver?
- What will you do if the weather is bad?

Your hospital stay

The average length of stay in the hospital after a transplant varies based on the type of transplant:

- **Kidney:** Three to five days
- **Heart:** At least two weeks
- **Liver:** One to two weeks

During that time, you will recover from surgery and learn about the post-transplant medications you will take and your new routine. Your support person(s) must also learn this information so they can help you after discharge. Starting the day after your transplant, your support person(s) will need to be available to attend education sessions.

After discharge

Once you are discharged from the hospital, you will need to make frequent trips to Hartford Hospital for lab tests and clinic appointments. You cannot drive for the first few months after surgery, your support person will need to take you to the lab for blood work and to Hartford Hospital for follow-up appointments. The first time you come to Hartford Hospital after your transplant, be prepared to stay for two to three hours.

Things to consider:

- How will you get to appointments/lab?
- What is your backup transportation plan?

Depending on where you live, you may want to stay close to Hartford Hospital at first, although we are unable to provide housing, meals or transportation. Hartford Hospital lodging discounts may be available.

You need to create a clear, realistic and affordable plan for this time.

Things to consider:

- Where will you stay?
- Who will you stay with?
- Do you have money set aside for lodging and/or meal costs?
- Does your insurance cover lodging, meals and/or mileage?
- Are you planning to fundraise to help cover transplant expenses? Before you start, check with your city or county governments, a legal advisor or Transplant Team about the legal and financial laws and guidelines.

How to help the transplant patient

Patients and families must have a plan for supporting the transplant patient. It does not have to be the same person for the entire period. Many families take turns caring for their loved ones. Some of the ways your help is needed are listed below.

Medication management

The number one priority for the support person is helping the patient take medications, which have complicated dosing schedules. The doctor and nurse coordinator may change the doses and medication often based on the patient's lab results and symptoms. **It is important to be available by phone so they can give you instructions.**

The support person makes sure the patient takes the right medications at the right time, which means fully understanding the medications, waking the patient if necessary to give medications on time, and talking with the Transplant Team about any side effects the patient is experiencing.

Activities of daily living

Patients need help resuming some activities and won't be up to the usual chores of food shopping, cooking or general household upkeep for a few months. Some patients don't have much appetite, or complain that food tastes different. As the support person, you need to fill in, doing the shopping, cooking and home care at first, while also making sure the patient eats well and gets enough fluids.

Some patients may need encouragement to move and walk to avoid serious complications; some may need to slow down and not overdo it. As the support, your job is to help the patient maintain moderate activity.

Emotional support

Transplant surgery is awe-inspiring, but no matter how smooth the journey or positive the outcome, it is also a crisis in that person's life and the life of their family. The emotional roller coaster many patients experience during transplant is hard to describe or predict. Sometimes, medication can add to the emotional ups and downs.

Most patients have intense emotions associated with transplant. They may experience unexpected guilt about getting a transplant before others who are waiting or about the donor's family. They may feel all of these emotions.

Often, waiting for transplant and the focus on staying alive prevents patients from making plans for the future or dealing with other problems in their lives. When they have the transplant, stored up emotions can flood in. Realistic fears of rejection and infection – as well as actual rejection and infection complications – affect patients' emotional state. They can be very frustrated with the road to recovery and the length of time it can take.

Being able to talk about potential frustrations is extremely helpful and having you be a good listener can do wonders for them. Patients absolutely require emotional support to make it through this very difficult time.

What patients don't need

- Most don't need help using the bathroom or taking a shower.
- Hospital beds.
- Help using the stairs and moving about, although they need to start slowly. On occasion, a patient may need to go to an acute rehabilitation center after the hospital if they have become very weak or lost too much strength during a long hospital stay. Patients who need a lot of medical support may need to be referred for nursing home care if they cannot participate in at least three hours of therapy a day.

Patients may be referred to home health care if they need IV antibiotics or other skilled nursing needs. This service brings a nurse to your home but only for a few hours some days of the week.

Tips for caregivers

- Get enough sleep, food, activity.
- Know your limits and ask for help and support when you need it.
- Take a break when you can.
- Use relaxation and/or humor.
- Keep a list of questions for the Transplant Team.
- Create a telephone tree or email list, or use social media to update people.

Summary

- The time right after surgery is challenging.
- Transplant patients need support around the clock for the first couple of weeks. The length of time they need this support depends on how quickly they recover.
- The patient is at risk for infection and rejection.
- It's important to identify back up supports in case a caregiver gets sick.
- The patient has to take a lot of medication, with potential side effects.
- It's essential to have open and regular communication with the Transplant Team.
- Remember that not only is the patient recovering from a huge surgery, but usually from years of illness.
- Emotional highs and lows are common: gratitude and joy at finally getting the transplant, but also fear of organ rejection, complications or even sadness and guilt.
- It can be frustrating for the patient to face the amount of time and work it can take to get back to "normal" and to realize there is a "new normal" as well. That's where a support person(s) can be incredibly helpful.

We're here to help

Members of the Transplant Psychosocial Team are available to support the transplant patient and caregivers. Please feel free to contact the social worker or nurse coordinator if you have any questions.

Hartford Hospital Transplant Center: 860.972.4219

Our Psychosocial Team includes:

Kidney transplant social worker

Jessica Bruneau, LCSW, CCTSW
860.972.114

Lisa O'Briant, LCSW
860.972.4425

Liver transplant social worker

Jenifer Riley, LCSW, CCTSW
860.972.5040

Living donor, heart transplant social worker

Laura Moehringer, LCSW
860.972.9934

Transplant Psychologist

Danielle Gleason, PsyD

Transplant Psychiatrist

Justin Uzl, MD

Hartford HealthCare
Hartford Hospital

Hartford Hospital Transplant Center **860.972.4219**

14162 4.20