

# Caring For Yourself After Discharge

When you leave the hospital after your transplant, you will go to a local hotel if you live more than 1 hour away. This is to be sure you will be able to return to the hospital promptly if you experience problems. Caring for yourself requires the support of your family, good common sense and following these instructions. The Resource Directory in this folder includes information about lodging.

## Daily Care and Activity

- ◆ Activity after discharge should be focused on increasing activity each day while incorporating some rest periods. Walking is an excellent activity.
- ◆ No driving, no lifting > 5 lbs.
- ◆ Do not return to work until cleared by the surgeon (usually 8-12 weeks).
- ◆ Use pain medications prior to starting am shower/care activity and prior to bedtime to reduce pain. While taking pain medicine drink plenty of fluid and use a stool softener like colace.
- ◆ Continue low salt diet if still on diuretics. No other limitations if weight is stable. If overweight: low fat, high fiber diet is recommended.

## Problems to Report to the Transplant Nurse on-call

- 1) Fever > 100.5 F, chills, nausea, vomiting (more than once), watery diarrhea

- 2) Inability to take medicines
- 3) New pain that is sudden or sharp
- 4) Drainage from wounds that is cloudy, has an odd smell or is very bloody. Pink-yellow fluid is OK.
- 5) T-tube comes out or is pulled partially out
- 6) No bile drainage or drainage that seems to have decreased dramatically.
- 7) Severe headaches not relieved with Tylenol or pain medicines.
- 8) You are admitted to the hospital at home for any reason.

## Wound and T-Tube/biliary Tube Care

- ◆ Staples from surgery will be in place for 3 weeks as steroids reduce tissue healing time.
- ◆ May shower with staples and tubes in place. Cleanse sites with antibacterial soap. Pat dry being careful not to pull. Do not use powder or lotion around incision or tube site.
- ◆ T-tube/biliary tube provides a "window" into the liver by which studies can be done to assess your liver's health. The tube provides support for the tissue where the two bile ducts (or the duct and the bowel) are healing. You will have this tube in place for an average of 6 months.
- ◆ Keep t-tube/biliary tube secure with square bandage (available at drug store) to prevent pulling on clothing.

## Contacting the Liver Transplant Nurse on-call

- ◆ Transplant Nurse Coordinators are available 24 hours a day, 7 days a week. We ask that you use your judgment to decide the urgency of your call.
- ◆ If the call can wait until normal business hours: call the transplant office at 919-684-6419. The office is open 8:00 am - 4:30 pm. If a coordinator is not available when you call, leave a message and your call will be returned. We ask that you call the office for things like prescription refills, non-urgent questions or anything that can wait for a response.
- ◆ If it is the evening, night time or the weekend and the call is urgent (like you are having the symptoms we just talked about) call 919-684-8111 and ask for the Liver Transplant Nurse on-call. Do not ask for the Surgery intern on-call or the attending physician.
- ◆ Stay on the line while the operator places the page. The call will be returned immediately and the operator will connect you with the coordinator.
- ◆ Please recognize that the nurses are not at the hospital during non-business hours. We are available for urgent needs. We want to attend to your needs in the most efficient manner possible.

Call the Transplant Coordinator on-call immediately if the tube comes out or is pulled out partially.

- ◆ If a bile bag is in place, you will be provided with an extra bag. Keep the tube open unless otherwise instructed. The nurse will show you the proper position of the stopcock. Use a safety pin through one of the holes in the top of the bag to secure to your shirt.

### **Preventing Infection**

- ◆ Handwashing, handwashing and handwashing are the keys to preventing infection, especially during the first year.
- ◆ Take your temperature 2 times a day for the first month after transplant. Consider early morning and late afternoon.
- ◆ Many people will want to visit when you return home. Be sure to ask people to visit at a later time if they have been sick or if members of their family have been sick recently. Avoid large crowds.
- ◆ If you have well water, ask your well company to treat the water for people who have suppressed immune systems.

### **Clinic Visits After Discharge**

- ◆ We keep a close watch on you especially during the first month after your surgery. You will stay in a local hotel or friend's home for two weeks if you must travel more than 1 hour to get home.
- ◆ Do not take your rejection medicine before clinic. You may take all other medicines. This includes Prograf (tacrolimus), Neoral (cyclosporin) and Rapamune (sirolimus).
- ◆ Bring a list of your medicines to each clinic visit.

- ◆ We will see you in clinic 2-3 times each week for labs and/or doctors visits. Frequency will depend upon your individual progress and concerns.
- ◆ When you are released to go to your home, you should plan to see your local GI doctor and family doctor when Duke visits are reduced to every 2-3 months.
- ◆ When you return home, you will be provided with doctor orders to take to your local MD or a local lab to have blood work done and results faxed to our office. Labs are imperative during the first year when your risk of infection and rejection are the highest.
- ◆ You should contact your local doctor for non-transplant issues or acute needs when your visits to our office are every 2-3 months.

### **Develop a Support System**

Your family will be your biggest support system after your liver transplant. There may also be others who you will have to help you such as friends or neighbors. They are welcome at anytime to come to clinic with you to learn more about the transplant, and how to care for you.

Another very good resource is *The Liver Connection* support group. Patients and their families who are waiting for liver transplant or who have had a liver transplant are invited to attend the support group. It is a safe place to share thoughts, feelings and experiences about liver disease and transplant. There are also educational presentations related to transplant. This group meets every Monday from 11:00 am-12:00 pm in the conference room across from clinic 2C. For more information, contact the liver transplant social worker

## RESOURCES

We want to help you and your family deal with concerns that may arise after your transplant. Your social worker, transplant coordinator, and physician can give you information on resources for your particular needs. The following list of resources may be useful. Please note there are hundreds of internet websites about liver disease and transplantation. We recommend only those we know will provide reliable information.

Duke University Health System  
[www.dukehealth.org](http://www.dukehealth.org)  
[www.organtransplant.duke.edu](http://www.organtransplant.duke.edu)

Organ Donation  
United Network for Organ Sharing  
[www.unos.org](http://www.unos.org)  
  
Carolina Donor Services  
[www.carolinadonorservices.org](http://www.carolinadonorservices.org)

Liver Disease  
Duke Liver Center  
[livercenter.mc.duke.edu](http://livercenter.mc.duke.edu)  
  
American Liver Foundation  
1-800-223-0179  
[www.liverfoundation.org](http://www.liverfoundation.org)

Transplant Information  
[www.transplanthealth.com](http://www.transplanthealth.com)  
  
National Foundation for Transplant  
[www.nft.org](http://www.nft.org)  
Information for fundraising

## PHARMACIES

You may select to use a local pharmacy in your hometown or a specialty mail-order pharmacy. Your insurance case manager can help decide which is the best option for you. If you will be staying in Durham after your transplant, we will give you two sets of prescriptions (for a local pharmacy and for your home or mail-order pharmacy).

## Local “Late-Night” Pharmacies

Eckerd Drugs  
7am–12mn M–F, 7am–11pm Sat, 8am–11pm Sun  
Corner of LaSalle Street & Hillsborough Road  
(919) 383-5591

Kerr Drugs - Loehmann’s Plaza  
8am–10pm M–Sat, 1–6 Sun  
Hillandale Road  
(919) 383-9428

There are also national pharmacy stores in Durham. The transplant coordinator may assist you to locate the closest one.

## LODGING

Most local hotels/motels offer discount medical rates, so be sure to mention that you are in Durham for medical care. A few offer special rates or services to transplant recipients; please ask your social worker for current information. Check with your insurance company prior to your transplant to see if it will offer you financial assistance with lodging if you need to temporarily relocate close to the hospital.

## Hotels with Suites/Furnished Apartments

Campus Arms	(919) 286-9133
Equity Corporate Housing	(800) 533-2370
Extended Stay America	(919) 489-8444
The Forest	(919) 383-8504
Homestead Suites	(919) 402-1700
Homewood Suites	(919) 401-0610

**Host Homes** (919) 684-5351

Sponsored by Pastoral Services and Durham Congregations in Action, this program assists patients and out-of-town family members with free or low-cost lodging in private homes in the area. Host Homes has been very supportive of our transplant recipients’ needs, but has a very limited availability. Your social worker

