

# Preparing for a Transplant

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We want to help you and your family prepare for your transplant. Making plans to deal with your needs before your transplant can reduce the amount of stress you will have to cope with during the recovery process. You will probably have to make some changes in your plan as your situation changes. Please keep us up to date on changes as they occur.

When you are called to come to the hospital for your transplant, it is vital that we be able to find you quickly at any time of the day or night. You need to have a reliable plan for getting to the hospital on very short notice. Once you have received your transplant and are ready for discharge from the hospital, you will be required to stay in the local area for 2-4 weeks. This gives the transplant team an opportunity to monitor your progress

closely through frequent clinic visits before you go home. It is important to plan for your needs during the outpatient rehabilitation stay. Also, it is important to make plans for obtaining your medicines. You will need to have your prescriptions filled before you leave the hospital.

Following are questions to help you in planning for your transplant. Please complete each question as thoroughly as you can. Once you and your family have had a chance to discuss your plans, you may need to schedule a time to discuss your plan and the resources you may need with your social worker, nurse coordinator, or financial coordinator.

## Transplant Planning

How will you get to the hospital when you are called for your transplant?

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Where will your family stay while you are in the hospital?

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Where will you stay locally after discharged from the hospital? Consider a place that will allow some meal preparation like a suite hotel.

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Who will stay with you since you cannot stay alone?

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Who will drive you to the Transplant Clinic for frequent visits?

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How will you pay living expenses for yourself and a family member/friend during those outpatient weeks?

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Who will take care of your home while you are away (pay bills, maintenance, pets, etc.)?

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Who will take care of your children while you are away from home?

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Who will pay for your transplant?

- Insurance       Medicare       Medicaid       Other

How much are your deductibles or co-payments? (How much will you be responsible for?)

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Do you have other concerns about your situation or your family in preparing for your transplant?

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Are there maximum limits on your coverage? Will your coverage change or convert?

- Are you under a COBRA plan?     Insurance     Medicare     Medicaid     Other

Who will pay for your medicines?

- Insurance     Medicare     Medicaid     Other

How much will you have to pay for your medicines?

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How will you budget for your co-payment or deductible?

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What pharmacy will you use?

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Are you registered with a transplant or mail order pharmacy (if you plan to use one)?

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What questions do you need answered by the transplant team?

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## **Liver Transplant Readiness**

When a donor liver becomes available for you, there is literally no time for delay. Therefore, you must be available to the liver transplant team members at all times. Your transplant coordinator will talk about methods for reaching you even when you are away from home. We will also obtain a list of relatives or friends who would know your location and how to reach you. While the actual amount of time that will be available for you to reach the hospital will vary, we generally ask that you be able to reach the hospital in six hours or less.

If you live farther away from Duke than a six hour drive, we will talk about faster methods of transportation or relocating to the Durham area. This may involve use of a helicopter or of a private charter jet service. Your transplant coordinator will help you decide which method of transportation will be the best for you.

When a donor liver has been identified for you, you will be called at home by the transplant coordinator. If there is no answer at your home number, we will try the other contact numbers you have given to us. You will need to come to the hospital as directed by the transplant coordinator.

Sometimes, after patients have arrived at the hospital and are ready for surgery, the transplant has to be canceled because the donor liver quality is not good enough. We hope this will not happen to you, but if it does, we will continue to care for you and prepare you for another opportunity. Having your transplant tentatively scheduled, then later canceled due to deterioration of the donor or liver has no negative effect on a future transplant.

## **Your Transplant**

When you receive your phone call from the transplant coordinator, she will tell you when to stop eating and drinking. You will be instructed to come to the Duke Hospital Emergency Room.

Upon arrival, you will be prepared for surgery. A chest X-ray, EKG, and routine blood tests will be done. After you are examined by the transplant team doctors and nurses, you may have some time to spend with your family before you go to the operating room.

Your operation will probably last from 6 to 10 hours. Your family will be shown where to wait and will be kept informed of your condition during surgery. You will be taken to the operating room on a stretcher. You will find that the operating room is cool and contains quite a bit of equipment. This equipment is used to monitor your lungs, heart and blood pressure during the surgery. You will also see many members of the team as they prepare you for the operation.

## **Liver Transplant Surgery**

The abdominal incision for your liver transplant is a large one. It starts at the base of your breast bone and goes out along the left and right rib cages. Once the transplant surgeons are notified that the donor liver is good, they will begin to remove your diseased liver. The diseased liver is totally removed only after the donor liver arrives in the operating room.

Connections, called anastomoses, attach the new liver. Once all the connections are made, your abdomen is closed and you are taken to the Surgical Intensive Care Unit (SICU).

Once the doctor has spoken with your family after the surgery, it will be 1.5-2 hours before they can see you in the ICU. This is a good time for them to try to call family members and friends at home, eat a meal or check into the hotel.

## **After Your Transplant**

### **The Surgical Intensive Care Unit Patient Care Area 2200**

Immediately following your transplant surgery, you will be brought from the operating room to the Surgical Intensive Care Unit (SICU). Once in the SICU, it will take

approximately one hour for the nurses to do their initial assessments and orders and help get you comfortable. The nurses will then call in your family members so that they may see you. You will still be somewhat sleepy because of the anesthesia. You may not remember most of your time in the ICU. After that initial visit, your family may see you during the SICU regular visiting times which are 10:30 am-6:30 pm and 8:30 pm-10:00 pm. Once you wake up, it is normal to feel confused. Your nurses will tell you that your surgery is over, and they will tell you what day it is, what time it is, and where you are. You may also still have a breathing tube in your mouth from surgery. However, the first priority is to remove the tube when you are ready. You will have many IV lines and tubes, and you will be in a room with many monitors and machines. Your hands may be loosely tied with soft restraints until you are fully awake, in order to prevent you from pulling out any of your tubes. Many patients do not remember the first few hours after surgery.

You will have a small tube in your nose that goes to your stomach, called a nasogastric (NG) tube. This tube will drain your stomach contents and help prevent you from feeling nauseated. The NG tube will be removed after your anesthesia wears off and your stomach and intestines begin to work again.

You will also have a large IV catheter in a vein in the side of your neck. This will allow us to monitor your heart function closely. You may have an IV in your arm for fluid or medication and another in your wrist to continuously monitor your blood pressure.

Pumps by your bed will be supplying you with fluid from the IV bags hanging overhead. This fluid contains various medications to control your heart rate and blood pressure. You will also be receiving IV medications to prevent rejection of your new liver.

You will have several drainage tubes in your abdomen. These tubes, designed to drain fluid and air from the space around the new liver, will be connected to suction bulbs for a few

days to help remove fluid more efficiently. The tubes will be removed within the first week after your transplant. Most liver transplant recipients have a special rubber tube called a "T-tube" placed in their bile duct during their transplant. This small tube allows bile to drain out of the new liver for several days. This helps your doctors monitor the function of your new organ. Several days after your transplant, a "T-tube cholangiogram" will be performed. This X-ray test involves injecting dye into your T-tube to check for leaks around the bile duct connection. If this test shows good healing of your duct, the T-tube will be clamped and your bile will drain into your intestine instead of outside your body (into a drainage bag). Keeping all of your bile helps you digest food better.

You will have a catheter in your bladder to drain your urine. Your nurses will measure and record your urine output every hour to ensure that you stay in good fluid balance. The bladder catheter will be removed within 2-3 days.

Finally, you will have a small sensor on your finger or earlobe connected to a machine at your bedside (called a pulse oximeter) to monitor your pulse rate and the oxygen level in your blood.

Every patient experiences pain after a major operation, but each person feels differently. Usually in the first few hours after surgery, you will get pain medicine through your IV. The nurses may give you this medicine or you may have a machine that lets you control when you get pain medication. Please let the nurses and doctors know if your pain is not being controlled, so that different treatment measures can be ordered.

Most patients stay in the SICU 24 to 48 hours before going to the Transplant Unit.

### **Physical Therapy**

While you are in the Surgical Intensive Care Unit your nurses will help you exercise your legs to reduce the risk of blood clots. After your breathing tube is removed, you will be

encouraged to turn, cough, breathe deeply, and expand your lungs to decrease the risk of pneumonia.

You will progress quickly to sitting on the side of your bed and dangling your feet, then to getting up in a chair within a day or two after your surgery. You will likely be able to walk by the second or third day. Physical therapists are available to assist you in progressive ambulation and exercise.

### **Intermediate and Stepdown Care Patient Care Area 2300**

When you are ready to leave the SICU, you will be transferred to the transplant surgery step-down unit. On this unit, you will continue to recover and regain your strength. Again, each person recovers at his or her own rate. As you recover, the IVs, drains, and dressings will be removed. You will have daily blood work so we can check for organ function and to see that your anti-rejection medicine is at the correct level.

Your physical activity will continue to be a priority. You will walk at least twice a day, increasing your distance each time. Most patients are able to walk one mile per day by the third or fourth week after surgery, and can go back to supervised treadmill and/or bicycle therapy in even less time.

Your education about how to care for yourself when you go home will begin once you leave the ICU. The coordinator will speak with you and your family about monitoring for infection, when to call the transplant team and other common post-surgical topics. The transplant pharmacists will teach you about your medicines and you will begin to take your medicines with the help of the staff nurses prior to going home.

You can expect to be discharged from the hospital within one to two weeks after your operation, but you will need to remain in Durham for another two weeks for frequent clinic visits. Remember that each person is different and your recovery depends on your progress or development of complications.

### **Caring for yourself after transplant will have special considerations.**

These include:

**Medications:** After a liver transplant, you will have medications to take for the rest of your life. These medications are very expensive and have some side effects. The financial

coordinator will explain insurance coverage or limitations. If you have limited insurance coverage for medications, you will be asked to fundraise for your future costs. The Financial Coordinator will direct you to resources for fundraising.

**Monitoring:** You will be asked to record your blood pressure, weight, temperature, and fluid intake and output each day.

**Healthy habits:** After the transplant, you will be expected to maintain a well-balanced diet and exercise regularly to keep yourself in good physical condition.

**Frequent check-ups:** You will need to return to Duke frequently for outpatient tests and Liver Transplant Clinic visits. You must also be seen by your local physician to provide routine and acute care.

Communication with the transplant coordinators about changes in your health before and after transplant is essential.

### **Your Long-Term Outlook**

While a liver transplant represents a great hope for people with end-stage liver disease, various complications can occur after liver transplantation. These may include rejection, infection, technical complications and recurrence of original liver disease.

During your hospitalization, we will teach you about your medicines, how to check your temperature, and monitor your incisions and drains daily. Often the first sign of liver dysfunction is seen in your lab work. That is why we ask you to come to the clinic frequently to monitor these values. Any changes in your liver function or other symptoms will be evaluated thoroughly. It is important that we carefully decide the cause of your symptoms so that we can treat you appropriately.

While complications are always a possibility, it's important to remember that the single most important factor in the outcome of your transplant is you. Liver transplantation is a lifelong commitment, one with lasting impact on every aspect of your existence. So take your responsibility seriously - and take good care of yourself.

The Duke Liver Transplant Team knows that going through a major medical procedure like this can be a trying time, and we want very much to help you through this process. Please let us know of any way we can help ease your confusion and anxiety. We look forward to working closely with you.