

# Maintaining Health While Waiting for Transplant

A new liver means new responsibilities. If we determine that a transplant would be the best treatment for your liver disease and you wish to proceed with a transplant, you will need to commit to caring for yourself to ensure the best health possible. This is a lifetime commitment.

Our goal prior to your transplant is to maintain the best possible health. Our whole team will be working very hard for this goal. We will act as your advocates and do everything in our power to get a liver for you. In return we expect you to be an active participant in your health-care. This means eating properly, exercising, quitting smoking, taking your medications as prescribed, informing us of any changes in your health, keeping you appointments and avoiding all recreational drugs and alcohol. You and your family are the keys to this goal.

While the time that you wait may be long, it is important that you speak with the nurse coordinators for any of the following:

- ◆ If you are hospitalized at home
- ◆ Your fluid or thinking are becoming altered or are worsening
- ◆ You notice you are more jaundiced or yellow in the eyes or skin
- ◆ You will be out of town for a period of time. Leave contact numbers with our secretary of how you can be reached. (919-684-6419)
- ◆ Your support system changes and you have nobody to help you.

A transplant is a very serious operation, and the better shape your body is in before the surgery, the less likely you are to have complications afterwards. This is why the team may be encouraging you to lose weight, exercise and stop smoking. Not smoking is extremely important because the medicines used to prevent rejection after transplant can increase your risk of developing cancer.

We have a “zero-tolerance” policy when it comes to alcohol and drugs. We may randomly screen you for drugs and alcohol or we may call you to report to your local doctor for testing. Randomly means that we can call you on any day and ask you to have bloodwork or to provide a urine sample. *If you are found to be using drugs (any type of illegal drugs or prescription medicine which we have stated is not acceptable) or drinking (any type of alcohol including beer and wine), you will be suspended (inactivated) from the waiting list for a minimum of six months.* You may also be required to enroll in a recovery program to become an active member of the waiting list. Three drug or alcohol related suspensions will result in permanent removal from our transplant waiting list. Please note that refusal to take a test when asked will be treated as a positive test by our team.

Similarly, failure to keep your appointments will be seen as a lack of commitment on your part. *The transplant team reserves the right to suspend (inactivate) you from the list for unexplained missed appointments.*

## Contacting the Liver Transplant Team:

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 call 919-684-8111 and ask for the Liver Transplant Nurse on-call. This would include notification of a patient becoming more sick or having new problems.
- ◆ 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.

## Routine Appointments

You will be seen by the Transplant team on a regular basis for review of your health and to prevent and manage any complications of your liver disease. It is important that you keep the appointments as scheduled especially if there are procedures or studies planned for your visit. If you cannot come to an appointment, you should contact the Liver Transplant Office. It is your responsibility to reschedule your appointment if you miss your appointment.

While you are waiting for your transplant, you should continue to see your local doctor for general health issues as well as new problems. Your local doctor should be the first person to help with acute problems. They can contact us to arrange urgent appointments if they think your symptoms require rapid evaluation by our team. In most cases, your local doctor can assist you.

## Medications

You should take medications as they are prescribed by your physician. Medications may be adjusted as needed depending on your illness or problem. If you need medication refills, you may contact the Liver Transplant office to request refills for medicines that are prescribed by the transplant team. Medicines prescribed by your local doctor should be refilled by that office.

Herbs, some nutritional supplements and other non-prescribed holistic remedies are highly discouraged. These products are not regulated or monitored by the Food and Drug Administration (FDA). We have no way of knowing the impact they have upon your health as a patient with liver disease nor the interactions with prescribed medications. Please talk about any of these products with the hepatologist or the nurse coordinator.

## Avoid Drugs and Alcohol

As previously discussed, we have a “zero-tolerance” policy about the use of alcohol and illegal drugs such as marijuana and cocaine. Prescription pain medicine abuse can also

be considered in this category. You may be randomly (that means at any time) tested for drugs in your blood or urine. If you are found to be actively using drugs or alcohol, your status will change to inactive for 6 months; we would not transplant you during this time. **There are no exceptions to this rule.**

## Develop a Support System

Your family will be your biggest support system while you wait and 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.

Another very good support 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

## Nutrition and Liver Disease

Everything we eat must be processed and cleaned by the liver. With a healthy liver, 85-90% of the blood that leaves the stomach and intestines carries important nutrients to the liver where they are stored or absorbed by the body for use. A healthy liver also produces bile, which is emptied into the intestines and helps to digest everything you eat. With a diseased liver, many of the normal functions of the liver are not performed well. When you cannot process nutrients from your liver and intestines, you may feel tired and weak. Fluid buildup in your abdomen, called ascites, may also occur because of abnormal blood flow to the liver. In the later stages of liver disease, your liver is not able to process protein-rich foods as well. This can lead to a buildup of ammonia in your blood stream causing the altered thinking known

as encephalopathy. Malnutrition is also a significant complication of chronic liver disease. Following specific dietary guidelines can decrease all of these complications of liver disease. The guidelines are as follows:

### **Limit sodium (or salt) intake in your diet.**

High sodium can lead to an increase in fluid buildup in the abdomen. Too much sodium can also cause fluid retention in other parts of your body, usually seen in the ankles. High sodium also causes increased blood pressure.

- ◆ Never add salt to food. Keep the salt shaker off the table.
- ◆ Do not cook with salt or salt containing seasonings. Use herbs and spices in cooking to replace salt.
- ◆ Avoid foods with visible salt like crackers, chips, pretzels, salted nuts, salted popcorn and salted french fries.
- ◆ Limit highly processed foods. Canned, preserved and processed foods contain high amounts of sodium. Watch out for processed meats, cheeses, canned soups, frozen dinners, and pickles.
- ◆ Limit dinner and side dish mixes that come with sauce or seasoning packages (like Hamburger Helper, Rice-a-Roni, macaroni and cheese, and au gratin potato mixes).
- ◆ Limit high sodium sauces (like soy sauce, canned spaghetti sauce, and packaged sauce, gravy and seasoning mixes).

### **Eat a healthy diet.**

It is important that you are in good nutritional health for liver transplant. You will recover faster and generally do better. When your body doesn't receive the nutrients it needs, it takes the protein from your muscles for energy. This causes weight loss and decreases in muscle mass and, therefore, strength. A balanced diet with adequate

calories, proteins, fats, and carbohydrates can help the damaged liver regenerate new liver cells.

- ◆ The diet should be high in complex carbohydrates (55-60% of calories), low in total fat (25-30% of calories) and moderate in protein (15 - 20% of calories).
- ◆ Five or six smaller meals should be eaten per day.
- ◆ Choose a variety of fruits and vegetables daily.
- ◆ Choose a variety of grains each day, especially whole grains.
- ◆ Choose a diet that is low in saturated fat and cholesterol and moderate in total fat.
- ◆ Choose beverages and foods to moderate your intake of sugars.

### **Aim for a healthy weight.**

- ◆ Being overweight increases your risk of developing diabetes, high blood pressure, and heart disease. Obesity can also cause complications with surgical wound healing following liver transplant. Eating a healthy diet and being physically active every day are very important for weight loss.
- ◆ Being below your ideal body weight for your height can also cause increases in malnutrition and surgical complications. Eating a healthy diet and being physically active are also very important to help gain weight and improve muscle mass.
- ◆ Your physician or dietitian will help you determine what a healthy weight is for you. Your dietitian can help you develop a meal plan for either weight loss or weight gain.

### **You may need to limit your fluid intake.**

Your physician will decide if this is necessary.

