

## Social Work Services

### *For liver transplant patients*

The transplant journey is a mixed experience, for you and for your family. On one hand, the transplant offers the hope of extending your life, improving your quality of life, or both.

But transplant also involves some risks and changes. You and your family will face some major challenges both before and after your transplant.

Your transplant social worker is trained to help you and your family understand and talk about the stresses that are part of the transplant journey.



*Your transplant social worker is an important resource for you and your family during your transplant journey.*

### What does a social worker do?

The transplant social worker is a member of the Transplant Team, and an important resource for patients and families. You and your caregiver(s) will meet with your social worker for a *psychosocial assessment* early in the transplant process.

### Psychosocial Assessment

This important consult is usually the first time you meet your transplant social worker. You and your support person will talk with the social worker about different aspects of your life. This will help the social worker support you and your caregiver(s) as you prepare for transplant.

This assessment process may take more than one meeting to complete. And, you may have many of these meetings before you are ready to be listed for transplant. Here are some of the topics you will talk about when you meet with your social worker:

- **Social situation:** Your social worker will ask you about your family history. This includes your family of origin, any cultural or religious beliefs, your current family structure, and your education, financial, and employment history.

- **Caregiver support system:** Your social worker will ask you to name a primary caregiver who will help you through the transplant process. This may be your spouse, partner, family member, or long-time friend. Many people may be willing to help you, but you will need to specify a main caregiver and bring this person with you to the Liver Transplant Education Class.
- **Your care plan before and after transplant:** Your social worker will explain what plans you need to make before you can be listed for transplant. Your social worker will give you an outline that you will use to address each step of your plan. You will need to fill out and return this document before you can be listed.

Some of the plans you will need to make involve:

- **Your transportation to and from UWMC,** both during the pre-transplant phase and when you are called in for the surgery.
- **How to communicate with your Transplant Team about any changes in your circumstances.** These changes could include hospital stays at other hospitals besides UWMC, and could be related to your housing, finances, or caregiver support.
- **Where you will stay after transplant.** For 3 months after discharge, you and your caregiver must stay within 2 hours of UWMC. Most people either stay with family and friends in the area or rent a furnished apartment during this time. Some people bring an RV or travel trailer and stay in a local RV park. Your social worker can give you resources to help you make these plans.
- **Housing and transportation costs.** If you have Medicaid funding, your benefits may help pay for housing and transportation costs. Or, you may want to try fundraising to help with these costs. Your social worker can give you information on fundraising groups.
- **Transplant teaching for your caregiver.** Before you leave the hospital, your caregiver will need to join you for the transplant teaching that takes place in your hospital room. This teaching often takes several visits and is set up on short notice.
- **Your caregivers.** After leaving the hospital, you will need the support of a full-time caregiver. Family members and friends often share this responsibility and take turns being the primary caregiver.
- **Getting to your follow-up visits.** Your caregiver should be able to drive you and come with you to your many follow-up visits after your surgery. You will need their help staying organized and keeping track of the instructions you receive from your healthcare providers.

## **Mental Health Issues**

If you have a history of mental health issues, your social worker may refer you for more evaluation. The goal of this evaluation is to provide you with the support you need for emotional stability during the transplant process.

## **Substance Abuse History**

Your social worker will also ask you about your use of various drugs:

- **Tobacco use:** If you use tobacco, you must stop using it or other forms of nicotine before you can be listed for liver transplant. You must make a lifelong commitment to never use tobacco or nicotine again, in any form.
- **Alcohol or illicit drug use:** You must make a lifelong commitment to never use alcohol or recreational drugs. If you have a history of alcohol or drug abuse or dependency, you may be asked to have more evaluations and meet other requirements before you can be listed for liver transplant.
- **Prescription pain medicine or benzodiazapine use:** If you are taking prescription pain medicine, are using sedatives like Valium or Xanax, or are on a methadone maintenance program, you will be asked to meet other criteria before being considered for transplant.
- **UWMC Substance Abuse Policy:** All transplant patients are asked to read and sign UWMC's Substance Abuse Policy. If you violate this policy at any time, you cannot be a transplant candidate or a re-transplant candidate at UWMC.

## **Support Groups**

At any point in the transplant process, you may attend the Liver Transplant Support Group. This group is informal and open to UWMC patients, their families, and their friends. Meetings include education about various transplant challenges and how to cope with them. The groups are led by UWMC transplant social workers.

The group usually includes people who are waiting for transplant and patients who have already had their transplant. It is an excellent way to hear from fellow patients about their experiences. It is also an opportunity to network with and gain support from others facing challenges that are similar to yours.

## **Counseling and Referrals**

Your social worker can also talk with you about:

- **Coping:** You will deal with many lifestyle changes and stresses before, during, and after transplant. If needed, your social worker will provide you referrals to agencies, community resources, or mental health professionals to help you cope with these changes.

- **Education:** Your social worker can provide information about the psychological, emotional, or social aspects of being a transplant recipient. This information includes written materials (such as from our lending library) and other resources related to transplant itself or to the many other larger issues that are involved.
- **Care plans:** Your social worker will help you solve problems on issues that come up as you create your care plan both before and after transplant. While you are in the hospital, your social worker may also help in your discharge planning.

After transplant, some patients need inpatient or outpatient rehabilitation, home health care referrals, or both. You, your caregivers, and your medical team will work together to make a plan for your care and for discharge after transplant.

- **Legal forms:** Your social worker will provide you with forms to create these legal documents for your medical record:
  - A **Healthcare Directive** (also known as a “living will”), which tells doctors your choices for end-of-life care.
  - A **Durable Power of Attorney for Healthcare**, which names a spokesperson(s) who would help make your medical choices if you were unable to communicate.

A more complete explanation of each document is included with the form. You may already have documents like these, or you might choose to work with your family attorney to create your own. But, many people use the forms as they are. The choice is yours.

Keep your originals of these forms in the same place you keep other important legal papers. Give copies of them to your social worker so that they can be placed in your UWMC medical record.

## Coping After Transplant

A transplant is a life-changing event for you, your family members, and your support person(s). During the first few months after transplant, it demands a major commitment for everyone involved. Your social worker and your entire Transplant Team are here to provide ongoing support and teaching for you and your caregivers.

You will receive support and teaching at each clinic visit before transplant, during your hospital stay, after transplant, and at each clinic visit after you go home. Many patients and their caregiver(s) report that attending the monthly Liver Transplant Support Group meetings at UWMC is helpful at this time as well (see page 3).

## Returning to a Normal Lifestyle

Our goal is for your life after transplant to be fulfilling, productive, and as normal as possible. This includes returning to work. Of course, a successful return to a job can help your financial situation and fill your health insurance needs. But also, patients who return to work both feel better about themselves and do better physically.

## Returning to Work

Most transplant patients are able to return to work after their surgery. The Transplant Team – and the Social Security Administration – expect that you will eventually return to work after transplant.

Some patients are able to continue working while they await transplant. Other patients have already been receiving Social Security Disability (SSD) or Supplemental Security Income (SSI) benefits due to disability caused by their health problems. Still other patients apply for these benefits after their need for transplant has been confirmed.

The legal definition of “disability” under the SSD and SSI programs is important to note: Disability is defined as:

“The inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death, or has lasted or can be expected to last for a continuous period of not less than 12 months ...”

Sooner or later after transplant surgery, most patients are no longer considered “disabled.” This means that you will probably lose your disability benefits after your transplant.

We encourage transplant patients to go back to work, but it is very important that you give yourself plenty of time to recover from your surgery. If you have a job that involves:

- **Only deskwork:** You may be able to go back to work on a part-time basis as early as 8 weeks after transplant.
- **Any physical effort or lifting objects that weigh 4 or more pounds:** You may not be able to return to work until 3 or 4 months after surgery, or as determined by your transplant doctor.

Before you return to work, please talk with your Transplant Team about getting a *medical release*. This is a form that says it is medically safe for you to return to work.

Some patients easily and successfully return to the jobs they had before transplant. If you can keep your employee status with your employer (either active or “on leave”) while you wait for transplant, you may have an easier time returning to work after your surgery. But, some patients may need help or retraining to re-enter the workforce.

## Barriers to Work

Some transplant patients run into barriers when they want to go back to work. Some employers may hesitate to hire a transplant patient. But, the law called “Americans with Disabilities Act” provides some protection from this discrimination. This law, and education, can help employers feel confident that transplant patients can be reliable employees.

## New Health Insurance

It can also be hard for transplant patients to get new health insurance. This makes it very important for transplant patients to have a plan for returning to work. If you want to return to work after your transplant, it is important to begin making your plans as early as possible.

## Writing to Donor Families

Many patients ask about writing to the family of their organ donor. Most families appreciate hearing from transplant recipients.

It is your choice whether to write to the donor family. If you do write, it is helpful to talk about yourself, your family situation, your job or volunteer work, your hobbies and interests, and your transplant experience and how it has changed and improved your life. And, don't forget to thank the donor family for their gift.

To maintain confidentiality:

- Please include your **first name only** in your letter.
- Do **not** include your address, phone number, email address, or other contact information.
- Place your letter or card in an unsealed envelope.
- On a separate piece of paper, write your full name and the date of your transplant. This information will be used to find your donor family, but it will not be given to them.

You can give your letter to your social worker, who will mail it to LifeCenter Northwest. This nonprofit organization manages organ donations in Alaska, Montana, Northern Idaho, and Washington. LifeCenter Northwest will forward your letter to the donor's family.

Or, you can send your letter directly to the organization. (Remember to include your full name and date of your transplant on a **separate** piece of paper from your letter.) Send your letter to:

### LifeCenter Northwest

Attn: Family Services Coordinator  
3650 131st Ave. S.E., Suite 200  
Bellevue, WA 98006

## Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:  
206.598.8882