

Social Work Services

For heart transplant patients

A heart transplant can be a mixed experience for you and your family. It offers a chance for a longer life and a better quality of life. But, there are also many risks, changes, and challenges you and your family may face both before and after transplant. Your cardiac transplant social worker is specially trained to help you cope with these changes and stresses.

Your Social Worker

Your social worker is an important member of your transplant team. This person is available to talk with you and your family during all phases of the transplant process.



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Psychosocial Assessment

A *psychosocial* assessment is usually done the first time you and your family meet with the social worker. You will all talk about various aspects of your life, including your family history and personal situation.

This information will be used to help you and your family prepare for your transplant.

The social worker will explain what your transplant team expects from you and will talk with you about your lifestyle, habits, social support system (family, friends, co-workers, fellow members of religious or spiritual groups), and financial and insurance resources. The social worker will also want to know what you expect from the transplant.

This evaluation process may sometimes take more than 1 meeting. It may be quite some time before you are ready to be listed for transplant.

Counseling and Referrals

You can attend a Transplant Support Group meeting at any stage of the transplant process. These meetings are usually educational, and they are led by a social worker. The group is informal, and it is open to UWMC patients and their families and friends.

Both pre- and post-transplant patients attend the support group. The meetings are a good place to get firsthand information about the transplant process from other patients. They provide a chance for you to build a support network of people who are facing challenges that are similar to yours.

Many patients find it useful to attend the Transplant Support Group meeting. This group was set up as a way for pre- and post-transplant patients to meet and talk about their experiences with the transplant process. The gatherings are held at UWMC once a month.

There is a separate support group for the families and caregivers of transplant patients. This gives your loved ones a chance to meet and exchange personal experiences with other people who are caring for transplant recipients. In addition, there are usually 2 social events each year where patients, their families, and the transplant team staff meet away from the hospital.

Your social worker can also meet with you privately to talk about lifestyle changes and stresses that may arise both before and after your transplant. If needed, your social worker can refer you to government agencies, community resources, or mental health services to help you cope with these changes.

Education

Your social worker can give you information about any psychosocial aspect of the transplant process. This may include written materials such as books and articles in the Transplant Lending Library or other information about services and resources. Your social worker can answer your questions about transplants and talk with you about the larger issues related to the transplant process.

Casework Services and Your Discharge Plan

Your social worker can help you deal with problems and issues such as your care plan for before and after transplant. Some transplant patients need extra financial help. Your social worker can help you find fundraising sources, get extra insurance coverage, and register with services provided by government or community agencies, if needed.

While you are in the hospital, your social worker may help you with your discharge plan. Many patients go directly home after their transplant. Some may need help finding a place to live nearby for the first weeks or months afterward. Other patients may need to go to a skilled nursing facility. Still others may need inpatient or outpatient rehabilitation or home health care providers. Discharge from the hospital is planned by the transplant team with your input as well as with input from your family and other caregivers.

Coping After Transplant

A transplant is a major, life-changing event for you, your family, friends, and others in your life. The first few months after transplant demand a great deal of commitment from everyone involved. The transplant team, including your social worker, is here to provide ongoing education and support for you and your family.

This support and teaching happens during your clinic visits before the transplant, after the transplant while you are still in the hospital, and at

Your transplant social worker can help you find resources to assist you with insurance, mental health, and counseling services. The social work team is here to assist you in coping with your life after transplant.

your clinic visits after you go home. Many patients find it helpful to attend the monthly Transplant Support Group meeting.

If you need more help dealing with the challenges of life after transplant, your social worker can also arrange referrals to mental health and counseling services in the community or at UWMC.

Returning to a Normal Lifestyle

The transplant team's goal is for you to lead a life that is as fulfilling, productive, and normal as possible. This includes returning to work if you are able. A successful return to work can provide income and, hopefully, reliable health insurance coverage. Studies have also shown that patients who go back to work not only feel better about themselves, but also do better physically.

Most transplant patients are able to go back to work after their surgery. Your transplant team and the Social Security Administration expect you to return to work when and if you can.

Some patients are able to keep working while they wait for a new heart. Others have already started getting Social Security Disability (SSD) or Supplemental Security Income (SSI) benefits if their health problems have kept them from working. Still others apply for these benefits once the need for a transplant has been verified.

The legal definition of "disability" under the SSD and SSI programs is important for you to know. Disability is:

*"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, most patients will no longer be considered legally "disabled." This means there is an increased chance of losing disability benefits. This is why it is important to have a plan to return to work if you are able.

While we encourage you to return to work after your surgery, you should also allow plenty of time to recover. Most transplant recipients can return to part-time jobs involving desk work (not physical labor) as soon as 12 weeks after transplant, depending on their progress. Some patients may be able to go back to work sooner, while others may need more time to recover.

If your job requires you to lift more than 5 pounds or do other physical activity, you will need 3 or 4 months of recovery time before returning to work. You will need to check with your transplant team before you return to work. Many employers will ask for a medical release form from your doctor before you start work again.

Most transplant patients return to work after their surgery. Your social worker can help you find vocational counseling and job training services if you are unable to return to your former job or type of work.

Some patients return to their former jobs quite easily. Patients who can keep their employment during the pre-transplant period, whether they are actively working or are on leave, tend to have an easier time going back to work after their transplants. Other patients may need retraining or other assistance to re-enter the workforce.

Some transplant patients may be ready to go back to work, but may not be able to return to the same type of job they had before their surgery. If this is true for you, UWMC has vocational rehabilitation services (including counseling, training, and advocacy) to help you get back to work. Vocational counseling can begin before transplant or shortly afterward to help patients find suitable jobs.

Returning to work can be challenging. Some employers may not want to hire transplant patients. The Americans with Disabilities Act of 1990 can protect you from this kind of job discrimination. This law, along with education and counseling, can help employers understand that heart transplant patients can be reliable, productive workers.

It can also be hard for transplant patients to get new health insurance. This makes it especially important for transplant patients to set up a “return-to-work” plan as early as possible. Meet with your social worker early in the transplant process to talk about the support services that are available to you. The most important step you can take concerning employment is to make a plan as early as you can to get back into the workforce.

Writing to Donor Families

Many patients have questions about writing to the family of their organ donor. For the most part, families are happy to hear from transplant patients. It is your choice to write to the family.

If you do write, it is helpful to tell them about yourself, your family, your job or any volunteer work you do, and your hobbies and interests. You may want to tell them about your transplant experience and how it has changed your life. Remember to thank the donor family for the gift of their loved one’s heart. If both you and the donor family agree, you may even wish to speak on the phone or meet in person at some point.

If you are not ready, do not feel that you must write to your donor’s family. And, the donor family may not be ready to hear from you. Both you and the donor family have been through life-changing events, which made the transplant possible. It can take time for everyone to process their emotions and be ready to share their thoughts and feelings with each other.

If you are interested in contacting the donor family, your social worker can provide a brochure explaining the process. This brochure also has a sample letter you might want to use as a guide.

You and your heart donor's family may want to write to one another after the transplant. If you are ready, your social worker can give you information about how to contact your donor family.

When writing to your donor's family, privacy and confidentiality are important. Please use only your first name. Do not include your address, telephone number, or any other contact information such as an email address. Place your letter or card in an unsealed envelope. On a separate sheet of paper, write your full name and the date of your transplant. Then give the letter to your social worker to forward on.

Or, you can mail it directly (in a second envelope) to:

LifeCenter Northwest Donor Network

Attention: Family Services Coordinator
1407 116th Avenue N.E., Suite E-210
Bellevue, WA 98004

LifeCenter Northwest Donor Network (LCNW) is the non-profit organization that manages organ donations in Washington, Alaska, Montana, and northern Idaho. LCNW will forward your letter to the donor family. For more information about LCNW and their organ donor program, call 877-275-5269 or visit the LCNW website at www.lcnw.org.

Questions?

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

Cardiology Clinic:
Weekdays 8 a.m. to 5 p.m.,
call 206-598-4300.

After hours and on weekends and holidays, call 206-744-2500. Say you are a heart transplant patient. A nurse will assess your problem and help you.