

Coping

Before, during, and after kidney/pancreas transplant

The transplant process can be very stressful before, during, and after your surgery. This chapter offers tips on coping that you may find helpful.

Coping with the Medical Workup

With so many tests and medical visits, the workup time can be stressful. You will see many UWMC staff and make many trips to the hospital or clinic before your transplant.

Use this time to:

- Learn as much as you can about what happens during the transplant journey. Many people feel more in control when they know what to expect. Feeling more in control may help you cope better.
- Explore all of your options. Weigh the risks and benefits of each choice you are given. **You** are the one who will decide what form of treatment you will have for your kidney disease.
- Take charge of your pre-transplant workup. Make sure all the tests you need to have are scheduled.

Finding Balance

Your wait for transplant may be long, but life cannot go “on hold” while you are waiting. Even after you are approved for transplant and put on the wait list, do your best to keep your life in balance. Here are some tips:

Physical Needs

- Keep active. Exercise helps maintain your health. If you have a physical disability, ask your doctor about special exercise programs.
- Work or volunteer if you can. People who work while waiting tend to have better outcomes after transplant.



Being active will help you cope while you are waiting for transplant.

Social Needs

- Stay in touch with your family and friends. Keep from getting isolated or lonely.
- Do your usual activities and hobbies, or try something new.

Emotional Needs

- Make sure you have a safe place where you can express your feelings, both the good and the bad.
- It is OK to feel sad, frustrated, and anxious. Share your feelings with a person or group you trust.

Intellectual Needs

- Keep your mind active. Try reading more instead of watching TV.
- Exercise your mind with a class, games, puzzles, or a book group.

Spiritual Needs

- If you are part of a spiritual community, stay involved.
- Rely on your beliefs for comfort and strength.
- Read, meditate, and do other things to increase your feeling of spiritual well-being.

Other Ways to Cope While Waiting

Adjust Your Attitude

- Stay positive. Positive thinking, humor, and leading a normal life all help people cope during a stressful time.

Receive and Give Support

- Be patient and gentle with yourself. You will likely need support more than ever at this time.
- You may need to rely on your support system in ways you never have before. Your personal support group can be very helpful as you go through your transplant. Involve those who will care for you all along the way so they will know what you will be going through. Use their support when you need it
- Know that transplant affects the whole family. It can change a family's lifestyle as well as your own.
- It can be easy to direct your anxiety and frustration at your caregivers. Reassure them that they are not the cause of your anxiety and frustration. Always thank them for their support.

Relax

- There are many healthy ways to relax when you feel anxious or stressed. Check out your local bookstore for books and tapes that may help.
- Ask your social worker for help finding a way to release tension.
- If you are having a hard time coping or feel you cannot handle it on your own, ask your doctor or social worker for a referral for counseling.

Social Work and Care Coordination Services

Your social worker is a member of your transplant team. Talk with your social worker at any time in your transplant journey, starting from your first visit.

Social Work and Care Coordination services include:

- **Psychosocial assessment:** At this visit, your social worker will meet with you and your support team to help you get ready for the transplant process. The social worker will ask questions about your lifestyle, support system, and financial and insurance resources. The social worker will also ask what you expect from your transplant experience.
- **Supportive counseling and referrals:** Counseling is available for you and your family or support person(s) during the entire transplant process. Your social worker can help with issues such as depression, anxiety, fear, stress, family problems, lifestyle changes, reactions to treatment, and stress from being in the hospital. If needed, your social worker will provide referrals to agencies, resources, or therapists.
- **Education:** Your social worker can teach you about or provide information about all personal and social aspects of transplant.
- **Casework services:** Your social worker can help you find local housing and assist with transportation and other issues after you are discharged from the hospital. They can also supply information about fundraising, getting insurance coverage, and working through problems with forms and complex health systems.
- **Information and referral to resources:** Ask your social worker for information and referral to resources such as Social Security, Washington State Department of Social and Health Services (DSHS), vocational rehabilitation, and local subsidized housing organizations.

Coping After Transplant

In the Hospital

Do your best to be patient while you are in the hospital after surgery. Focus on going home. Your transplant team will tell you what you need to do to be able to go home and when it is safe to do so.

After Discharge

Mood changes and strong emotions are normal after transplant. They may be caused by side effects of medicines. They can also be caused by the stress of surgery. Be sure to tell your caregivers that these ups and downs are common.

Some feelings you may have are:

- **Anxiety and depression:** You have had medical and nursing care 24 hours a day in the hospital. When you go home, you will have to do things on your own at home, with help from your caregivers. Use your caregivers, ask for support, read your discharge instructions, and ask questions. Always know that you can talk with someone 24 hours a day by phone, if needed.
- **Guilt:** Some patients have “survivor’s guilt.” This is a feeling of regret that someone had to die for them to receive an organ. Some patients feel guilty that because they got an organ, it means someone else did not. Others feel they did not deserve the suffering that led to the need for a transplant. These are all normal feelings. If you are bothered by these feelings, please talk with someone on your transplant team.
- **Stress:** The weeks after transplant can be stressful. Your life revolves around medicines, clinic visits, lab tests, and worries over organ rejection and infection. Most patients say that it gets much easier over time. Ask for help if you have concerns about how you are doing.

Give yourself time to recover from surgery and the changes you have gone through. Returning to a “normal” lifestyle will take time and patience.

It may also take friends and family time to adjust to the “new” you as a healthier, more independent person. You can help them by getting better and taking great care of yourself.

Writing to the Donor’s Family

Many transplant patients want to write to the family of their donor. Most donor families welcome hearing from the transplant recipient.

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, and your hobbies and interests. Share how your transplant experience has changed and improved your life. And of course, thank the donor family for their gift.

To maintain privacy, please include only your first name in your letter to the donor family. Do **not** include your address, phone number, email address, Facebook page, or other personal information.

When you are ready, give your letter to your social worker or transplant coordinator. We will forward it to the donor family.

Questions?

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

Transplant Services:
206.598.3882