Coping

Before, during, and after your kidney/pancreas transplant

The transplant process can be very stressful. There is no one right way to prepare or cope. The stress can occur at any time before, during, and after your transplant. This chapter offers tips on coping that others have found helpful.

Coping with the Medical Workup

With so many tests, the workup time can be stressful. It is a time when you will see many UWMC staff.

Use this time to gather as much information as you can about what you will go through during transplant. Many people feel more in control when they know more about what to expect and what will happen. Feeling more in control may help you cope better.

Look into all of your medical options. After all, you decide what form of treatment you will have for your kidney disease. Be in control of your pre-transplant workup, and make sure all the tests recommended for you are scheduled. Weigh the risks of each option available to you.

Coping While You Wait

Your wait may be long, and your life does not stop or go on hold during this time. Even after you are approved for transplant and put on the waiting list, be sure to balance all of your needs:

- **Physical:** Keep active. Exercise will help maintain your health. There are special programs for people who are physically disabled. Work or volunteer if you can. Studies show that those who work while waiting do better after transplant.

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

- **Emotional:** Make sure you have a safe place where you can express your feelings – the good and the bad. It is OK to feel sad, frustrated, and anxious. You need to be able to share your feelings with a person or group you trust.

- **Intellectual:** Keep your mind active so that you do not lose mental function. Try reading more instead of watching TV. Exercise your mind with a class, games, puzzles, or a book discussion group.

- **Spiritual:** If you are part of a spiritual community, stay involved. Your beliefs can be a source of comfort and strength.
Paying attention to these things will also help you cope while waiting:

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

- **Support:** Be patient and gentle with yourself. You will likely need support more than ever at this time. And, 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. Transplant affects the whole family. It can change a family’s lifestyle as well as your own. Patients often direct their anxiety and frustration at their caregivers. Besides keeping them involved and using their support when you need it, also let them know they are not the cause of your anxiety and frustration. And, always thank them for their support.

- **Relaxation:** There are many healthy ways to relax if you feel anxious or stressed. Your local bookstore will have books and tapes that may be helpful. Contact your social worker if you need help choosing or learning a relaxation technique.

If you are having a hard time coping or feel you cannot handle it on your own, ask for a referral for counseling. Your doctor or social worker can provide a referral.

**Social Work and Care Coordination Services**

Your social worker is a member of your transplant team. Your social worker can provide services from your first visit through your follow-up care.

Social Work and Care Coordination services include:

- **Psychosocial assessment:** This is a time when the social worker meets with you and your support system to help you all prepare for and understand the transplant process. The social worker will ask questions about your lifestyle, support system, and financial and insurance resources. The social worker will also want to learn about what you expect from your transplant team.

- **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, and reactions to medical treatment and 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 any psychosocial aspect of transplant.

• **Casework services:** Social Work and Care Coordination can help you find local housing and can help with issues related to discharge from the hospital, including transportation. They can also supply information about fundraising, getting insurance coverage, and working through problems with paperwork and complicated systems.

• **Information and referral to community resources:** Ask your social worker for information and referral to community resources such as Social Security, Washington State Department of Social and Health Services (DSHS), vocational rehabilitation, and local subsidized housing organizations.

### Coping After Transplant

Be patient while you are in the hospital. 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.

Mood changes and emotional ups and downs are common after transplant. Sometimes they are caused by side effects of medicines. They can also be caused by the stress of what you have just gone through. Be sure to tell your caregivers that these ups and downs are common.

Some common feelings when going home from the hospital are:

• **Anxiety and depression:** You have had care 24 hours a day in the hospital and now you will have to do things on your own at home. Use your caregivers, ask for support, read over your discharge instructions, ask questions, and always keep in mind that you can talk with someone 24 hours a day by phone, if needed.

• **Guilt:** Some patients have what is called “survivor’s guilt.” This is a guilty feeling that someone had to die so they could receive an organ. Some patients feel guilty knowing that if they got an organ it means someone else who was waiting 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 period after transplant can be stressful. Your life can revolve around medicines, clinic visits, lab tests, and worries over organ rejection and infection. This is normal. Most patients report that this gets much easier over time. Ask for help or reassurance if you are concerned about how you are doing.
Give yourself time to recover from surgery and the changes you have gone through. Meeting your goal of 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 Donor Families

Many patients have asked about writing to the family of their organ donor. Most donor families greatly 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 of course, thank the donor family for their gift.

To maintain confidentiality, please identify yourself by your first name only and do not include your address, phone number, or other contact information. Give your letter to your social worker or transplant coordinator to send to the donor family.