



如何应对

肾脏/胰脏移植之前、过程中及移植后

移植的过程不论是移植之前、过程中、或移植后都会很有压力。本章节为您提供一些应对的提示可能对您有些帮助。

应对各项医疗的检测

因为要做很多的测试、门诊、所以在这段检测的期间会感到有压力。在移植前您也将与很多华大医疗中心 **UWMC** 的职员见面、多次到医院来或门诊。

您可利用这段时间：

- 尽量学习有关移植过程。很多人认为知道过程、以后会发生些什么事就觉得自己正在掌握。觉得自己在掌握就可能有助于应对。
- 咨询您所有的医疗选择。权衡每一种可能性的风险及益处。以何种方法来治疗您的肾脏病是**您的**选择。
- 由自己来掌握移植前的各项检测、也确认各项需要做的检测都安排好预约的时间

寻求平衡

您可能会等很长的时间、而在这段时间您的生活不可能“停摆”。即便是上排名了、还是对您生活保持平衡。下面是一些提示：

身体方面的需要

- 保持活力。锻炼可以维持身体健康。对有残障的人也有特殊的锻炼项目。
- 如可能就上班或作义工。等待期间工作的病人、移植后复原的情况较好。



保持活跃有助于等待移植期间的应对

社交方面的需要

- 与家人及朋友保持联系。避免将自己孤立起来或孤单。
- 作您平常的活动保持您的嗜好、或尝试新的东西。

情感方面的需要

- 确认您有一个安全的地方可以坦诚地谈论您的感觉不论是好的或坏的。
- 可以感到忧伤、沮丧、焦虑；因此您需要有一个或一组您可以信任的人来分享分担。

智能方面的需要

- 保持思考的活力。避免只看电视、可以多读书籍。
- 以上课、游戏、拼图或书籍讨论小组等等来训练您的思考力。

心灵方面的需要

- 如您参与一个属心灵的团契、就持续参与。
- 依靠您的信仰它可成为您的安抚及力量。
- 阅读、沉思及做其他事情，以增加您的心灵健康的感受。

等待期间的其他应对建议

调整心态

- 保持乐观。积极的思考、幽默和过正常的生活都有助于人们在压力下应对。

接受及给与支持

- 对自己要有耐心不要苛求。这可能是您最需要扶持的时段。
- 也可能是您第一次要如此依靠您的扶持者。您个人扶持团队的支持有助于您度过移植的过程。请您的护理人在一开始就参与、这样他们就知道您将经历的过程。您在需要时、就借重于他们的支持。
- 移植是影响全家人的。它会同时改变您的生活型式也改变您家人的生活型式。
- 病人很容易把他们的焦虑及沮丧对着他们的护理人发作。请他们了解您不是对他们不耐烦或发脾气。时时记着谢谢他们的帮助。

放轻松

- 当您觉着焦虑及有压力时、是有很多健康的方法来疏解的。您当地的书店就可能有书籍或磁带可以对您有助益。
- 如您需要协助如合缓解压力、可联系您的社工。
- 如您应对有困难、或您觉得不能独自面对、就要求转荐看辅导。您的医生或社工可以为您转荐。

社工及医疗协调服务

社工是您移植组的组员。您的社工可以从您第一次来诊到以后的后续护理一直为您服务。

社工及医疗协调服务包括：

- **社会心理评估：**社工与您及您的支持组员见面、以便协助您预备移植的过程。社会工询问一些您生活的形式、支持组员、健保等资源。社工也希望了解您对移植组的期盼。
- **支持的辅导及转荐：**在整个移植的过程、您及您的家人或照顾者都可咨询我们的辅导服务。如有忧郁症、焦虑、恐惧、压力、家庭问题、生活形式改变、医药治疗的反应、及住院等问题、您的社工可以为您服务；包括为您转荐到其他服务单位、提供资源或治疗师。
- **学习：**社工可以教导或提供有关如何预防与移植相关的心理问题。
- **个案的服务：**您的社工可以协助您寻找本地的住所、及出院后的各项事务包括交通。他们也可提供募款、取得健保涵盖、如何处理复杂的文件问题等等的资讯。
- **资讯及转介到社区资源：**向您的社工获取资讯及转介到社区的各种资源如社会保险、华州福利局 (DSHS)、职业复健、及您当地房租补助机构。

移植后的应对

住院期间

在医院期间需要耐心。将目标放在回家上。移植组的医生会告诉您需要能做到那些事后就可回家、也会告诉您什么时候才能安全地做这些事。

出院后

移植后情绪的变化、心情的起伏是很常见的。有时它们是由药物引起的。也可能是由于手术所带来的压力。请告诉您的照顾者、这种起伏是正常的。

您可能感到：

- **焦虑及忧郁：**在住院期间 24 小时有人照顾您、现在您回家了什么都需要自己来。借重于您的照顾者、请人协助、再看几次出院须知、提问、请记住、如需要倾诉、您全天 24 小时都可以电话联系。
- **内疚：**“幸存者的负罪感”。有些病人抱有所谓的愧疚感、因为另一个人必须死去，才使他们能够接受器官。有些患者感到内疚、知道如果他们得到了一个器官就意味着其他还在等待的人没有得到。还有其他人觉得他们根本就不应该这么受苦、以致需要进行移植手术。这些都是正常的感情。如果您被这种情绪困扰，请告知您的移植组员。
- **压力：**移植后的时间会很有压力。您的生活好像就是围绕着药物、门诊、血液测试，以及忧虑器官排斥及感染。大多数病人说渐渐的就会容易得多。如果担心您适应有问题、就寻求帮助。

手术后的恢复及改变的适应都需要时间。要达到您为自己订的恢复“正常”的指标是需要时间及耐心的。

同时您的亲友也需要时间来习惯/适应一个更健康、更独立的“新的”您。您可以致力于康复地更好、好好地照顾自己来鼓励他们。

写信给捐赠者的家属

很多病人想写信给他们捐赠者的家属。大多数的家属都非常感谢接受移植器官者的信件。

这是由您选择是否要写信给捐赠者的家属。如您要写信、可以谈谈有关您自己、您的家庭情况、您的工作或义工的服务、您个人的兴趣及爱好、您移植的经验、以及它如何改进了您的生活。当然、也感谢捐赠者的家人的礼物。

为了保持个人隐私、请只用您的名字不用姓。也不要写地址、电话号码、电邮地址、脸书/微信/社交网络帐号或其他联系的资讯。

请将您的信交给您的社工、或您移植联系人。我们会转交给捐赠者的家属。

您有疑问吗？

我们很重视您的疑问。当有疑问或顾虑时，请致电您的医生或医护人员。

移植科电话：
206.598.3882

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