

Coping with a Transplant

This booklet was written to help patients, and their families, and caregivers recognize and cope with stress before or after transplant.

It includes information about:

- Common causes of stress before and after transplant
- Tips on coping with stress
- How to access the Transplant Psychosocial Team
- Recommended resources to learn more



Introduction

It is normal for patients and family members to feel a range of emotions during the transplant journey. Many people have positive emotions such as hope, elation, and gratitude. It is also normal to have difficult emotions such as fear, sadness, anxiety, irritability, anger, and grief.

This booklet was created to help you prepare for the stress that may happen before and after transplant, to learn skills to cope, and to help you feel confident and comfortable accessing the supports that are available to you.

This information is not only for patients but also for caregivers, who can experience [stress and burnout](#) during the transplant journey.

Stress and transplant

Stress is a normal part of life, and is expected during life changing events such as organ transplant. Too much stress, though, can have a negative affect on your physical and mental health.

According to the National Cancer Center Network, distress is an “unpleasant experience of mental, physical, social, or spiritual nature.”

Some symptoms of distress may include:

- fear and anxiety
- helplessness
- anger
- questioning your purpose in life
- withdrawing from loved ones
- frequent thoughts about your illness and death
- trouble sleeping
- trouble concentrating

“Stress symptoms cause an extra burden of suffering, on top of the suffering caused by your health condition. They can worsen your health symptoms. They can make it difficult to attend medical appointments, keep up with self-care, or stay active.”

- Bilsker, Samra, & Goldner, 2009

The image below shows the link between living with a health condition and stress.

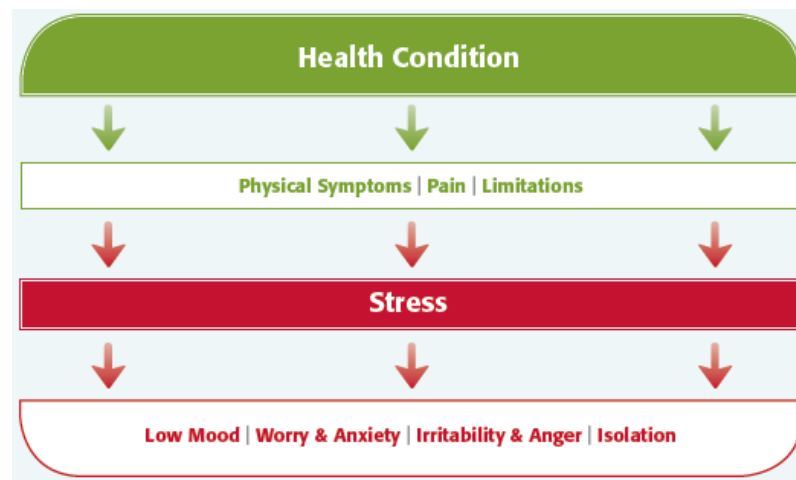


Image used with permission: © 2009 by D. Bilsker, J. Samra, & E. Goldner from Positive Coping with Health Conditions: A Self-Care Workbook (full text available from the Centre for Applied Research in Mental Health and Addiction).

Waiting for, or living with, a transplant puts you at a higher risk for depression and anxiety. Other than the stresses related to health, things like finances, relationships, and work, can also affect the stress levels in your life.

Before Your Transplant

The period before your transplant includes when you are assessed for an organ transplant and the time you spend waiting on the transplant list. Some people wait a long time for their transplant. Others may experience a rapid decline in their health, which may lead to an urgent transplant.

Here are some common reasons that may cause stress while you are being assessed for or waiting for your transplant. As you read them, you may want to check off those that you relate with.

Feelings of guilt:

- Thinking that someone has to die for you to receive an organ.
- Feeling like you are a burden to others.
- Blaming yourself for your disease.

Lifestyle changes that can cause stress:

- Symptoms of your organ disease, such as confusion, shortness of breath, low-blood sugar, dizziness or fatigue.
- Living with the medical treatments and side effects that impact your quality of life. This might include taking new medications that have unpleasant side effects, monitoring your blood sugar and giving yourself insulin, dialysis, or carrying oxygen tanks or mechanical devices.
- Having a hard time following the recommendations made by your health team, such as physical activity guidelines, fluid or diet restrictions, or abstaining from alcohol or cigarettes.
- Loss of sex drive or ability due to your physical condition, side effects of medication, changes in self-esteem, or emotional health.

Fears and anxiety:

- Worrying about what may happen in the future.
- Worrying about having a long hospital stay.
- Waiting for assessment results or to be placed on the transplant list.
- Being called in for a transplant, and finding out the organ was not a suitable match for you (false alarms).
- Being in denial that you need an organ transplant.
- Fear of dying before a donor organ becomes available.
- Worrying about not surviving the surgery or about potential risks.

Social or relationship stresses:

- Loss of control over your life (choices, careers, school, or time).
- Lack of support from family or friends.
- Feeling isolated and alone, like no one else understands.
- Financial problems.
- Feeling helpless and dependent on others.

Other causes of stress before transplant

Use this space to note down any other reasons you may feel stressed:

After Your Transplant

The period after your transplant includes your hospital stay and recovery time after your surgery. This involves managing your anti-rejection medications and getting used to life at home after your transplant.

Here are some common reasons that may cause stress in the time after your transplant. As you read them, you may want to check off those that you relate with.

Hospital stay stressors:

- Feelings of confusion or [delirium](#) after your surgery.
- Staying in the hospital for a long time, maybe longer than planned.
- Complications from surgery, or new medical issues after transplant.
- Pain and discomfort.

Anti-rejection medications:

- Emotional side effects of anti-rejection medications, such as anxiety, confusion, depression, irritability, or trouble sleeping.
- Changes in how you look and your self-esteem, related to the side effects of anti-rejection medications.
- Worrying about missing doses or taking the wrong medication at the wrong time.

Feelings of guilt:

- Feeling guilty about having depression or anxiety after your transplant.
- Being unsure of how to fully express gratitude or feeling indebted to your living donor, or a deceased donor's family.
- Feeling guilty about receiving an organ, knowing others who may have passed away while waiting.
- Wondering where the donor organ came from.

Adjustment to life after transplant:

- Feeling too dependent on others and wanting to get back to being independent.
- Feeling that your recovery is slow and that it is taking a long time to get your physical strength back to normal.
- Feeling worried about leaving the hospital and returning home.
- Feeling that your family or friends do not fully understand what you have gone through.

Living with a suppressed immune system:

- Dealing with new lifestyle restrictions on activities like travelling, eating, taking supplements, or being out in the sun.
- Fear of organ rejection.
- Fear of infections and illnesses.

Other causes of stress after transplant:

Use this space to note down any other reasons you may feel stressed:

Tips to Reduce Stress

We are all unique and have different ways of dealing with difficult times in our lives. It is common for patients and families to forget about taking care of their emotional and mental health during the ups and downs of their transplant journey.

Learning strategies to help you cope with difficult emotions, thoughts, physical health issues, and life circumstances can help to [reduce stress](#).

Here is a list of some ways you can manage your stress related to your transplant.

Balance your perspective:

- ✓ Some people say that 'someone has to die for me to live' when they think about transplantation. But the reality is people pass away every day. The families who donate organs often feel a sense of joy and relief that their loss can save the lives of others.
- ✓ Recognize that some of these changes are temporary. While it may take a few months after transplant to feel 'normal' again, things will get better over time.
- ✓ Try not to compare yourself to other patients. Everyone's transplant journey is different.
- ✓ Try to challenge unhelpful or worrying thoughts with more realistic ones.
- ✓ For example, instead of thinking: 'What if I get sick and miss another family dinner?' Say to yourself: 'I have been taking my medications, and at my last clinic visit I was told that I was doing well. My family loves me and they understand my medical issues. Even if I do get sick, I can still video conference them.'
- ✓ Be kind to yourself. Remember you have gone through a lot already. Only you really know how much you've been through!
- ✓ Try to keep your sense of humour, even during difficult times.
- ✓ Accept what you can't change and that you might have to temporarily give up some of your day-to-day roles and responsibilities.

Take control of your health:

- ✓ Consider [using technology](#) to track, organize, and set reminders about appointments, taking medications, tracking your weight or physical activity.
- ✓ Keep track of your health records and appointments by signing up for [myUHN Patient Portal](#).

- ✓ Use a pill box or organizer (dosette) to keep track of your medications or ask your pharmacist to put your medications in a blister pack to make things easier.
- ✓ Learn about the [common side effects of transplant medications](#). Knowing what to expect will help you to know when to take action and seek care or support.
- ✓ Take the lead on your health. Advocate for yourself by speaking to your medical team about your any questions or issues you are experiencing related to your emotional or physical health.
- ✓ Seek out rehabilitation options and exercise within your limits.
- ✓ If you smoke, take steps to quit smoking by joining a [smoking cessation program](#) or asking your primary care provider or pharmacist for support.
- ✓ Seek help if you or your family is worried about your [drug or alcohol use](#).

Self-care:

- ✓ Try out new, meaningful activities and hobbies within your physical abilities. Or, revisit an old hobby that brings you joy.
- ✓ Make healthy [sleep habits](#) a priority.
- ✓ Write down your experiences to reflect on later or to share with others.
- ✓ Practice mindfulness or yoga at home, or at a studio or community centre.
- ✓ Try [relaxation strategies](#), breathing exercises, and meditation or grounding skills.
- ✓ Get creative! Try out adult colouring books, playing or listening to music, painting, or other arts and crafts to relieve stress and express your feelings.
- ✓ Try and find a small pleasurable activity or do something kind for yourself every day, even if it seems small.
- ✓ Use [health and wellness mobile apps](#) to keep you on track and manage your symptoms and health.

Give back:

- ✓ Consider volunteering your time or giving back to the community in some way. For example, there is a [high school outreach initiative](#) to raise awareness about organ donation.
- ✓ Think about writing an anonymous letter to your donor. Ask your transplant coordinator for help if you are having difficulty [writing your donor thank-you letter](#) after transplant.
- ✓ Share your appreciation with your caregivers and health care team.
For example, you might wish to send a card, letter, or simply say 'thank-you'.

Connect with others:

- ✓ Talk to your loved ones about how you feel.
- ✓ Share your story with others.
- ✓ Spend time with the people who matter to you the most.
- ✓ Join a local or online support group.
- ✓ Find a community through social media, such as Facebook, Instagram or Twitter.

Other ideas for coping with your stress:

How to Get Help

We urge you to speak to your health care team if you are not feeling like yourself, or are feeling [depressed](#) or [anxious](#). We are here to support you.

Transplant Psychosocial Team

UHN has a [Transplant Psychosocial Team](#) who provide emotional and practical support to patients and families before and after transplant. The team is made up of mental health nurses, social workers, and psychiatrists.

You can access the Transplant Psychosocial Team by asking your transplant coordinator or doctor for a referral.

Website: https://www.uhn.ca/Transplant/PatientsFamilies/Clinics_Tests/Transplant_Psychosocial_Team

Spiritual Care Team

During your stay at Toronto General Hospital, there are also [spiritual care](#) practitioners who are here to offer support. Let your care team know if you would like to connect with a Spiritual Care Practitioner.

Help in the community

Many of our patients live outside of the Greater Toronto Area. In some cases, we can set up Telehealth appointments for urgent consultations with the Transplant Psychosocial Team. Our team can also help you to find local resources supports as you cope with the stress of transplant.

Finding help yourself:

Here are some suggestions if you would like to seek additional support on your own:

- Speak to your primary care provider (family doctor or nurse practitioner) about support resources in your community
- If you are a patient of a Community Health Centre or Family Health Team, ask if there is a social worker who can help you navigate community supports.

- Find a social worker to speak to using findasocialworker.ca. They can help you to access financial support, drug coverage information, and other helpful resources.
- Join a support group in the community for people living with organ disease, chronic illness, or transplant.
- Join an online support group, or find a community of people to connect with on social media, such as Facebook, Instagram or Twitter
- Visit the TGH Patient and Family Library and speak to a librarian. They can help you to find information about your condition, healthy living and more. You can pick up brochures or borrow books and eResources.
- Visit the [UHN Transplant](http://uhntransplant.ca) (uhntransplant.ca) website for helpful information about preparing for, or recovering from, transplant.
- Connect with spiritual or religious leaders in your community for support and guidance.
- Seek out a counsellor or therapist.
- Ask your care team for a referral to a local Mindfulness-Based Stress Reduction (MBSR) program.

Community and Online Resources

[UHN Patient & Family Libraries](#)

UHN offers health information services to patients, families, and members of the community.

[TGH Patient & Family Library](#)

Location: 1st Floor, Norman Urquhart Building
Next to the Outpatient Pharmacy
and Medical Imaging

Phone: 416 340 4800 ext. 5951

Email: tgpen@uhn.ca

Website: uhnpatienteducation.ca

Trillium Gift of Life Network – [Transplant section](#)

Information for those waiting for an organ or tissue transplant or those who have received the gift of life.

Phone: 1 800 263 2833

Website: www.giftoflife.on.ca/en/transplant.htm

[theHealthLine.ca](#)

Access to local community, mental health, and support resources in Ontario.

[Anxiety Canada](#)

Website promotes awareness and offers resources.

[211](#)

Government and Community resources.

Phone: Dial 211

Website: 211.ca (Canada-wide)

211ontario.ca (Ontario)

211toronto.ca (Toronto)

[ConnexOntario](#)

Access to local addiction, mental health, and problem gambling services.

An email or online chat options are also available.

Phone: 1 866 531 2600

[Mental Health App Library](#)

A list of apps for sleep, anxiety, depression, and relaxation, put together by The Scarborough Hospital.

[Positive Coping with Health Conditions](#)

A free workbook to learn to cope with health conditions.

[Big White Wall](#)

An online mental health and wellbeing service for people living in Ontario.

BounceBack[®] Program

A free skill-building program designed from the Canadian Mental Health Association (CMHA) to help adults and youth (15 years and over) manage symptoms of depression and anxiety.

Catch Your Breath! A guide to lung transplant for families and support people

A booklet created at UHN for families and support people of lung transplant patients. Use the link below or visit UHN.ca and type "Catch Your Breath" into the search box.

From Illness to Wellness: Life After Transplantation

A booklet (PDF) from the National Kidney Foundation.

Recommended Reading

The TGH Patient & Family Library on the 1st Floor of the Norman Urquhart Building (next to the Outpatient Pharmacy) has many of these items available to borrow. Visit or contact the Library to learn more about borrowing, or to access more information about transplant and healthy living.

Caregivers, children and families

Medikidz Explain Kidney Transplant: What's Up with Jonah?

by K. Chilman-Blair (2012)

Medikidz Explain Organ Transplant: What's Up with William?

by K. Chilman-Blair (2010)

Organ Transplants: A Survival Guide for the Entire Family

by T. Schwartz (2015)

Our Transplant Journey: A Caregiver's Story by R. Moore (2011)

Take a Breath: A Transplant Journey by K. Kelly (2016)

Heart

I Think I Need a New Heart: The Journey from Heart Failure to Transplant by M. Kalia (2017)

Journey of the Heart: Spiritual Insights on the Road to a Transplant by E. A. Bartlett (1996)

100 Questions & Answers about Liver, Heart, and Kidney Transplantation by H. M. Gilligan (2011)

Kidney

Warriors and Heroes of a Different Kind: Battling Kidney Failure by P. Stanbury (2018)

The Kidney Donor's Journey: 100 Questions I Asked Before Donating My Kidney by A. Sytner (2016)

Liver

100 Questions & Answers about Liver Transplantation: A Lahey Clinic Guide by F. D. Gordon (2006)

Life Goes On: Journey of a Liver Transplant Recipient by C. Jowett (2015)

Not Done Yet: A Tale of Transformation Through Transplant Surgery by S. L. Willen (2014)

Lung

Swimming through Adversity: Surviving a Lung Transplant by G. Maitland (2018)

Taking Flight: Inspirational Stories of Lung Transplantation – More Journeys by J. Schum (2011)

Breathless: A Transplant Surgeon's Journal by T. R. J. Todd (2007)

Emotions and coping

Coping with an Organ Transplant: A Practical Guide to Understanding, Preparing for, and Living with an Organ Transplant

by E. Parr, & J. Mize (2001)

The Dance of Fear: Rising Above Anxiety, Fear, and Shame to Be Your Best and Bravest Self by H. Lerner (2005)

Mind Over Mood, Second Edition: Change How You Feel by Changing the Way You Think by D. Greenberger (2015)

The Relaxation & Stress Reduction Workbook

by M. Davis, E. Eshelman, and M. McKay (6th edition - 2008; 7th edition - 2019)

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Visit www.uhnpatienteducation.ca for more health information.

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