

Coping with a Heart Transplant

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

It includes information about:

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

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Disclaimer:

The information in this booklet does not replace the advice or counsel of a doctor or health professional. Each individual responds differently and your course may not be exactly as described. You should consult with, and rely only on the advice of, your physician or health professional.

The information in this document is intended solely for the person to whom it was given by the health care team. If you have questions, please talk to a member of your team.



*Remember, every person recovers differently.
Not everyone progresses at the same rate.*



Coping with a Heart Transplant

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our thanks to all.

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This material has been
reviewed and approved by
patients, families and staff.



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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 process.

“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

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 effect on your physical and mental health.

Some symptoms of stress may include:

- fear and anxiety
- feelings of helplessness
- anger or irritability
- muscle tension or headaches
- questioning your purpose in life
- withdrawing from loved ones
- frequent thoughts about your illness and death
- trouble sleeping
- trouble concentrating
- feeling emotional & crying more than usual

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



Living through the transplant journey puts you at a higher risk for depression and anxiety. In addition to the stresses related to health, things like finances, relationships, and work, can also affect the stress levels in your life.

EMOTIONAL AWARENESS & REGULATION

The first step of learning to regulate your emotions is to be able to notice and name them. Using the Emotion Wheel on the next page, go through these steps.

You can use the worksheet page_ to guide you through the steps.

Step 1: NOTICE	Pay attention to how you feel, or when you start feeling stressed or scared. What do you notice in your body? Or in your mind?
Step 2: NAME	Label the emotion that you are feeling (you can use the wheel). Does this emotion fit with the physical feelings your noticed?
Step 3: ALLOW	Can you accept this emotion? Just allow it to be and ride it out?
Step 4: NEED?	What is this emotion alerting you to? Anxiety might mean you need some reassurance or a sense of safety. Sadness, you need comfort. Anger may suggest you need to put up a boundary.
Step 5: ACTION	What can you do to meet the need you noticed in Step 4?

FEELINGS CHECK IN

What feelings do I notice? (Use the wheel to name them)

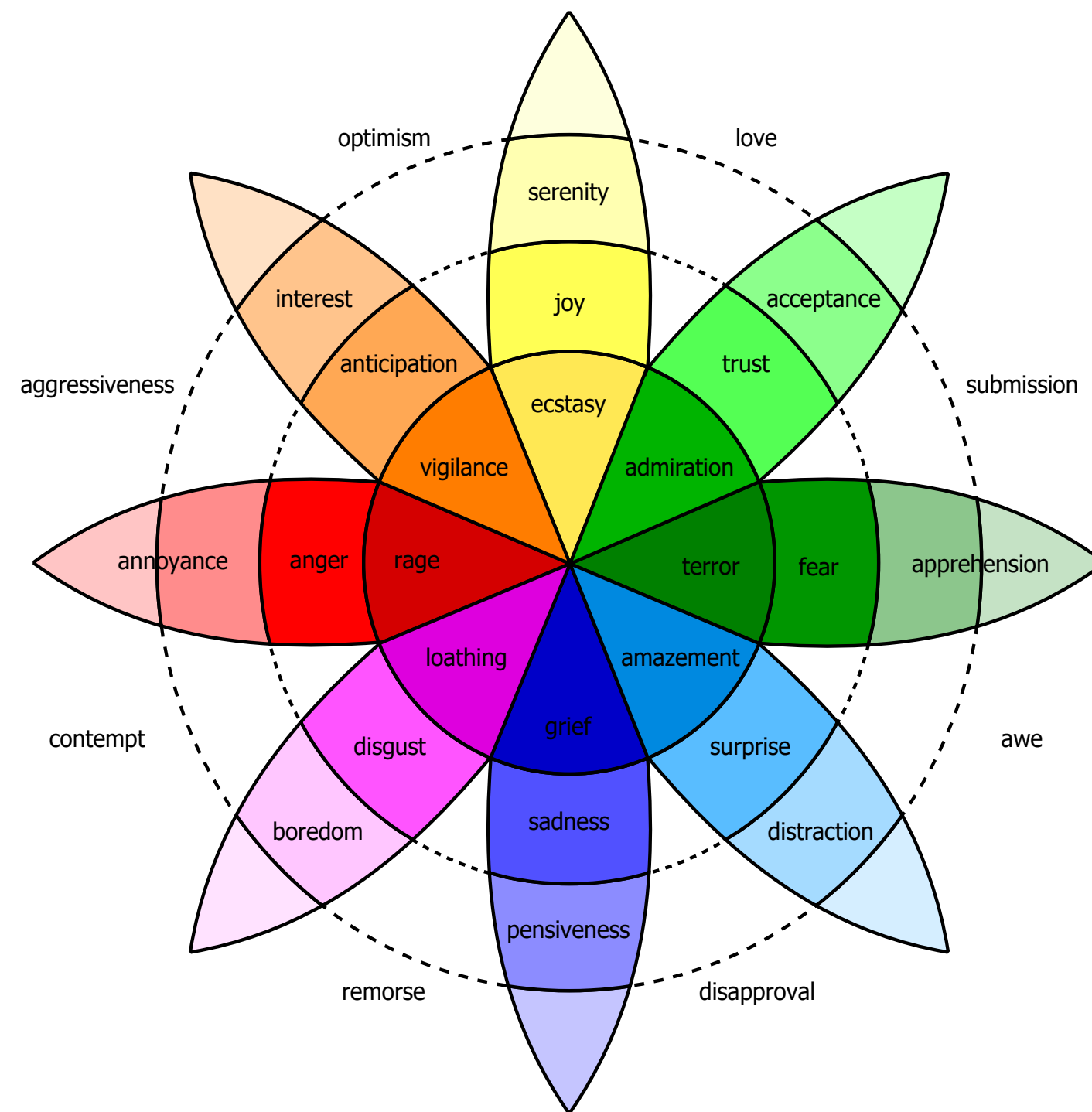
What do I need?

What can I do right now about it? (the answer might be to merely ALLOW the feeling)

HINT – Consider using the STOP skill or PAUSE button (on the next 2 pages)

USE THE FEELING WHEEL TO INCREASE YOUR AWARENESS OF YOUR EMOTIONS

Being aware of your emotions is the first step before you can understand or manage them. Look over this image, and use the worksheet on the next page to increase your awareness.



Feeling Wheel – R Plutchik, 1980

STOP SKILL

The STOP Skill is helpful when you are starting to act impulsively without thinking. It is to stop yourself from REACTING and saying or doing something you might regret later. Practice this skill so that it becomes second nature. You want the STOP skill to be readily accessible when you are feeling overwhelmed.

1. **Stop! Don't react. Freeze! Don't move a muscle. Your emotions want you to react without thinking. Stay in Control!**
2. **Take a deep BREATH.** Take a break. Let go. Take a step back from the situation.
3. **Observe.** Notice your thoughts and feelings. Notice what others are saying and doing.
4. **Proceed mindfully.** Act with awareness. Think about what will help make the situation better, rather than worse.

PAUSE BUTTON

Grounding is a technique that helps us reorient to the here-and-now, to bring us into the present.

This is very useful if you ever feel overwhelmed, intensely anxious, or angry. The "54321 game" is a sensory awareness exercise that many find a helpful tool to relax or get through difficult moments.



Take a few deep breaths while you:

Name 5 things you see in the room.

Name 4 things you can feel ("my feet on the floor" or "the air in my nose")

Name 3 things you hear right now ("traffic outside")

Name 2 things you can smell right now (or 2 smells you like)

Name 1 good thing about yourself

You should feel calmer and more at ease by the end of the exercise. Repeat the 5 steps more than once if needed.

Try out the technique in different situations, you may find it works well for insomnia, anxiety, cravings when quitting smoking or for general relaxation.

Radical acceptance

Acceptance takes time. Dr. Kristin Neff (2018) and other researchers have described five stages in coming to full acceptance. This is all about learning to accept what is - to not fight your reality.

Resisting - Struggling against what is happening. This is not helpful, but is a common reaction to negative events, emotions and sensations.

Exploring - Turning toward discomfort with curiosity. "What am I feeling?"

Tolerating - Safely enduring. "I don't like this. But I can tolerate it."

Allowing - Letting your feelings come and go.

Befriending - Seeing the value in difficult emotions, and enduring difficult life moments. "What can I learn from this?" "What can my loved ones learn from this?" "What is the silver lining?"

Helpful Thinking Strategies

Some people say that 'someone has to die for me to live'. But the reality is that 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. This results in them experiencing more positive meaning from the death of a loved one.

It's important to recognize that some of these changes are temporary. While it might 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 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 with 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.

Try to accept what you can't change and that you might have to temporarily give up some of your day-to-day roles and responsibilities.

Please keep in mind that much of this is easier said than done. Our program psychologists are ready to help you!

***"Grant me the Serenity to
ACCEPT those things I cannot
change,
The Courage to CHANGE the
things I can,
And the Wisdom to know the
difference."***

-Reinhold Niebhr

Take control of your health:

- Consider using an app to track, organize, and set reminders about appointments, taking medications, tracking your weight or physical activity.
- 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. And use an alarm to remind you when it
- Taking your anti-rejection medications exactly as prescribed and on time, every 12-hours, is the NUMBER ONE thing you can do to ensure a good long life post-transplant.
- Take the lead on your health. Ask your medical team about any 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. Ask your transplant nurse, psychosocial team or your primary care provider for help if you need it.

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. Ask your nurse about how to connect with the BC Transplant group on Facebook.

Self-care:

- Try out new, meaningful activities and hobbies within your physical abilities. Or, revisit an old hobby that bring you joy.
- Make healthy sleep habits a priority. Consider a referral to a program psychologist if you need assistance. A great book for learning how to manage insomnia is “Goodnight Mind.”
- 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 mobility 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, you can volunteer for the BC Transplant society.
- Think about writing an anonymous letter to your donor. Please see the Communicating with the Family of Your Organ Donor brochure developed by BC Transplant. If you have not yet been provided with a copy of this, ask your program nurse or the Social Worker.
- 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’.

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

St. Paul’s Hospital 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 psychologists, social workers, and psychiatrists. You can access the Transplant Psychosocial Team by asking your nurse or doctor for a referral.

Spiritual Care Team

During your stay at St. Paul’s 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 Vancouver Area. We can set up Telehealth appointments for those who live far from the hospital. Our team can also help you find local resources and 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.
- Join an online support group, or find a community of people to connect with on social media, such as Facebook, Instagram or Twitter
- Connect with spiritual or religious leaders in your community for support and guidance.

Resources

Positive Coping with Health Conditions is free workbook to help with cope with health conditions.

BounceBack© Program is 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.

Recommended Reading

Caregivers, Children and Families:

Organ Transplants: A Survival Guide for the Entire Family

by T. Schwartz (2015)

Our Transplant Journey: A Caregiver's Story

by R. Moore (2011)

Heart Transplant:

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)

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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How you want to be treated.

www.providencehealthcare.org