

# SUPPORTING YOURSELF WHILE SUPPORTING OTHERS: A WELLNESS MANUAL FOR TRANSPLANT CAREGIVERS

A resource ceated by the Transplant Wellness Program, in partnership with the Health and Wellness Lab and clincal experts.









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# **HOW TO USE THIS RESOURCE**

The role of caregiving is a critical and demanding position across the transplant journey. As a caregiver, it can be easy to put your own needs aside. Prioritizing your wellness can reduce your risk of burnout, stress, and allow you to be a better support person.

In this manual, we provide evidence-based resources and examples for skills you can use to support you as a caregiver.

#### PHYSICAL ACTIVITY:

Physical activity is one of the best evidence-based ways to reduce stress, increase energy, and improve quality of life. This manual provides information on the recommended amounts of physical activity for adults as well as tips for choosing activities that match your energy and fatigue.

#### **SOCIAL SUPPORT:**

Supporting a loved one through a transplant can be a daunting and isolating experience. Connecting with others who have also "been through it" can help you feel less alone. This manual links to an online support group and a testimonial from a fellow transplant caregiver that you may find beneficial/supportive.

#### **GOAL SETTING:**

Goal setting is a skill you can use to identify what parts of your wellness are important to you and build plans to achieve your goal. This manual provides information on the importance of goal setting, how to set goals, and some space for you to set a wellness goal for yourself.

#### **JOURNALING:**

Journaling is a self-care method that can help improve wellness and alleviate mental distress. Tips for getting started on journaling and prompts are provided to support you in this process.

#### **BREATH WORK:**

Breath work is a quick wellness technique that can be done anywhere and helps you remain grounded and present. This manual provides instructions on how to perform different breath work techniques and links to guided breath work practice.

#### **SELF-COMPASSION:**

Self-compassion is the ability to treat yourself with love and kindness when faced with a challenging situation. Self-compassion can help you navigate the uncertainty and stressors of caregiving. In this manual, you will find resources on self-compassion and examples you can practice.

# CANADIAN 24-HOUR MOVEMENT GUIDELINES FOR ADULTS

# **PHYSICAL ACTIVITY**

#### **Aerobic**

## 150 min/week

- Moderate to vigorous intensity
- Aim for 30 min bouts
- Can be broken into 10-15min bouts instead
- e.g., brisk walking, swimming, tennis

#### Resistance

### 2x/week

- Major muscle groups
- Aim for 8 12 reps
- Older adults need to incorporate balance
- e.g., strength training with body weight, dumbells, resistance bands

# **Balance and Flexibility**

#### Daily

- Aim for most days of the week
- Balance is critical for older adults
- e.g.,yoga, stretching



Even small steps towards these targets will positively impact your health



# **SLEEP**

It is recommended to get 7 to 9 hours of quality sleep per night. With a regular bed time and wake up time

# SEDENTARY BEHAVIOUR

Aim to limit sedentary time to 8 hours or less per day, this includes:

- Limit recreational screen time to 3 hours or less
- Take frequent breaks from prolonged sitting



(Canadian Society for 4 Exercise Physiology, 2025)

# THE RED, YELLOW, AND GREEN LIGHT EXERCISE SYSTEMS

Our stoplight system is used to help you choose physical activity or exercise that is going to be the best for your body on any given day, given your energy and fatigue levels, and management of your personal symptoms and side effects you might be experiencing due to the demands of caregiving. This system helps to ensure that you have choice – exercise or movement is never "all or none" – so you can always choose some movement to match your energy and fatigue levels.

The Red Light is for when you have higher fatigue and lower energy. These are the least intense activities, that you do for the shortest amount of time.

The Yellow Light is for the days when you have moderate energy and fatigue levels. These are the mild to moderate intensity-level activities, and of a bit longer duration.

The Green Light is for when you feel full of energy and are up for a challenge. These are the exercises that you would do for longer, at a higher intensity (moderate to even vigorous), and perhaps with adjustments to make them slightly more challenging.

The goal of following this system is to ensure exercise has a positive impact on your energy and does not increase your fatigue. Exercise is beneficial when what you are doing is a 'match' for your body.

# THE RED, YELLOW, AND GREEN LIGHT EXERCISE SYSTEMS

#### Red

- Light effort
- Feeling unwell
- High fatigue
- Choose activities that are shorter in duration & lower in intensity

#### Yellow

- Moderate effort
- Feeling okay
- Moderate fatigue
- Choose activities that are moderate in duration and intensity

#### Green

- Strong effort
- Feeling good
- Low fatigue
- Choose activities that are longer duration & higher in intensity

Example activities when using the Red, Yellow, and Green Light System

#### Red

- Walking around your house for 5-10 minutes
- RPE of 1-2/10
- 10 min of supine (lying down) stretches, and supine exercises such as ankle pumps, heelslides, glute bridges and lower trunk rotations.

#### Yellow

- Walking around the neighbourhood for 10-20 minutes
- RPE of 3-4/10
- . 6-8 exercises
- One set of 8-12 repetitions
- Consider an easier modification

#### Green

- Walking, cycling or otheraerobicactivity for 30+ minutes
- RPE of 5-6/10
- 8-10 exercises using large muscle groups
- Two sets of 8-12 repetitions



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# **Caregiver Support Group**

# AN ONLINE SUPPORT COMMUNITY

Caregivers Alberta is a non-profit organization that supports caregivers across the province. Their online program allows you to connect with other caregivers. A place to find support, education, and common understanding of the challenges of caregiving. Sharing common experiences and connecting can help the caregiving journey feel less isolating.





# WHAT TO EXPECT AS A CAREGIVER



# Click here to view the TWP caregiver Interviews on YouTube

Being a caregiver to a transplant patient can be an isolating experience. We have collated a series of videos from fellow caregivers to offer support and share stories of their journeys. These caregivers elaborate on their caregiving experience, how they prioritized their own wellness, and advice they would give to other caregivers starting out in their caregiving journey.

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# **GOAL SETTING**

Prioritizing your wellness while caring for a transplant patient can be challenging. Many people find that having a goal in mind gives them something to work towards, helps them in the face of overwhelming demands, and offers a clear way to measure their self-care.

Using goal-setting frameworks, such as MOVE, can help you connect to your important outcomes.

MOVE stands for: Motivation, Opportunity, Value, and Enhance



# SETTING MOVE GOALS

# **MOTIVATION**

What is your motivation to engage in this behavior?

- "I want to stay physically active while caregiving so I can help my loved one recover."
- "I want to feel less stressed so I can enjoy the activities I did before caregiving without feeling guilty."

# **OPPORTUNITY**

What **opportunities** do you have to engage in this behaviour? What barriers do you need to address?

• "I can dedicate 10 minutes dedicated to stress reducing activities (journaling, deep breathing, mediation).

# **VALUE**

Which core values does this goal relate to?

 "Prioritizing a weekly self-care activity aligns with my value of taking control of my own health and wellness"

# **ENHANCE**

What aspects of your life would achieving this goal **enhance**? (Physically, mentally, emotionally, socially)

- "Engaging in regular self-care activities will improve my mood and reduce my anxiety"
- "Being more mindful will allow me to have more energy throughout the day to do the things I enjoy"

# SETTING MOVE GOALS

**(YOUR TURN!)** 

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VALUE
Which core <b>values</b> does this goal relate to?
ENHANCE
What aspects of your life would achieving this goal <b>enhance</b> ? Physically, mentally, emotionally, socially)

# CONSIDER THESE POINTS WHEN DEVELOPING YOUR GOALS:

## **Set specific long-term and short-term goals:**

Short-term goals will be good at different stages of your caregiver journey (for example, you might have a specific self-care goal once your loved one is home from the hospital to prioritize your health). A short-term goal can help keep you motivated and on track to reach a longer-term goal (for example, progress to 10 minutes of deep breathing and journaling a day)

## **Challenge yourself:**

Make your goals manageable but ambitious enough that you are proud of the accomplishment when you meet your goal.

#### Focus on the process:

Outcome goals are the end results that you want to achieve. Process goals are developed to help get you there - the smaller steps used to achieve a longer-term outcome goal. An example of an outcome goal is: "By the end of 8 weeks, I will have journaled once a week and done deep breathing activities once a week." It can be motivating to set a shorter-term process goal, such as: "For the next week, I will schedule a time to do 3 minutes of deep breathing and 10 minutes of journaling."

## Re-evaluate your goals regularly:

At different points across your timeline, you will need to adjust your goals. Your goals may look different before your loved one's transplant, inhospital, and post-transplant. Adjust your goals as you move through your self-care journey

**Example:** "My goal is to journal for 10 minutes and do a deep breathing activity for 3 minutes once per week. My goal is to do this for the next four weeks."

# **Navigating The Caregiving Journey**

# **JOURNALING: A POWERFUL SELF-CARE TOOL**

Journaling is a self-care practice that can help to improve wellness. Evidence has shown that journaling can reduce burden and increase wellness in a number of caregiving populations (Tapper, 2023). Journaling can follow a variety of formats, such as identifying emotions and writing about stressful situations, or practicing gratitude. There is no right or wrong way to journal - you can try out different methods and strategies and see what works best for you!

## Tips for starting out:

- 1. **Keep it brief**. Even 5-10 minutes a day can make a difference. Keep it easy, don't feel pressured to write pages and pages.
- 2. Any Format Works. A simple notebook, a notes app on your phone, or a dedicated journaling app are all great options. Choose what feels easiest to access.
- 3. No Rules: This is your space. Say what is on your mind, don't worry about grammar or spelling. Just let your thoughts flow freely.



# JOURNALING PROMPTS TO GET STARTED

1. Today's Intention / Focus:						
What is one thing I want to focus on or achieve today?						
2. Morning Reflections / Starting the Day:						
How am I feeling right now (mentally, emotionally,						
physically)? What's on my mind as I begin the day?						
3. Key Events / Experiences of the Day:						
What were the most significant things that happened						
today? (Big or small)						

4. Moments of Gratitude:
What am I grateful for today? (Try to list at least 3 things
5. Challenges / Lessons Learned:
What challenges did I face today? What did I learn from them?
7. Evening Reflections / Looking Ahead:
How am I feeling now at the end of the day?
What do I need to let go of from today?
What is one thing I'm looking forward to tomorrow?



# Stress Reduction Resources BREATH WORK

Deep breathing is a mindfulness technique that can help with relaxation and stress reduction. There are a variety of different types of breath work, with two common practices known as diaphragmatic breathing, or "belly breathing" and box breathing. These breathing techniques can help shift your body and mind from a tense fight-or-flight response into a calmer state.

With the stresses of caregiving and uncertainty surrounding transplant, you may notice feeling more stressed or anxious than usual, signaling your body might be in a fight-or-flight response. Integrating breathwork into your routine may help to reduce some of the stress you may be experiencing as a caregiver.





# Videos for Breathing Techniques found on YouTube:

<u>Learn Breathing Technique Box Breathing: Practice</u>
<u>Breathwork for Focus and Anxiety with Dora Kamau</u>

<u>Breathing Technique to Relax: Belly Breathing</u>
Exercise with Dora Kamau





# Stress Reduction Resources BREATH WORK

**Exercise: Box Breathing** 

Begin standing, seated, or lying down. Pick whichever position is most comfortable. Release any tension you are holding in your body

To begin, follow this breathing pattern:

- 1.Inhale slowly through your nose for four counts, focusing on your belly expanding.
- 2. Hold your breath at the top for four counts.
- 3. Exhale slowly and controllably through your mouth for four counts.
- 4. Hold your breath out for four counts. Repeat this cycle until you achieve a state of relaxation.



# **SELF-COMPASSION**

As you start your **self-care journey** and gradually integrate more wellness practices, keep in mind that daily and weekly changes in how you feel are useful tools for guiding your continued wellness journey. One of our mantras is to **give yourself grace**. This is critical to navigate any 'bumps' along your journey. Giving yourself grace is about self-compassion – giving the same kindness to ourselves that we would give to others.

The three elements of self-compassion:

# 1. Self-kindness vs. self-judgment

Being warm and understanding towards shortcomings and difficult experiences. Treat yourself the way you would treat a close friend who is struggling.

# 2. Common humanity vs. isolation

Suffering and personal inadequacy are part of the shared human experience. Being imperfect, failing, and experiencing life difficulties are inevitable.

## 3. Mindfulness vs. over-identification

Non-judgmental, receptive mind state in which one observes thoughts and feelings as they are.

# **SELF-COMPASSION**

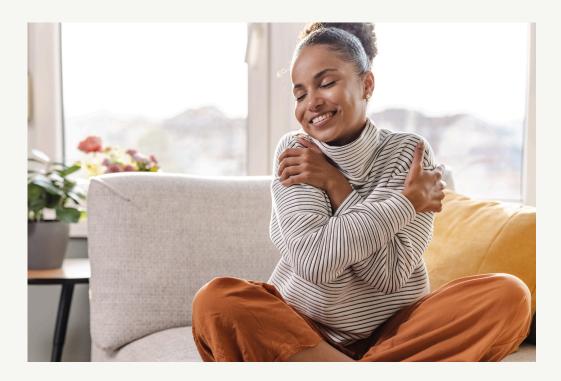
For example, you can bring attention to the present moment by trying any of the following:

Focusing on your breath. Try any of the breathwork practices referred to earlier in this manual such as box breathing, brining your focus to the present.

Noticing sensations on the soles of your feet. This centering practice brings focus to a physical part of your body, so that you can let other thoughts simply 'move' through your mind.

Savouring the taste, smell, feeling from drinking a cup of tea. Focusing on multiple sensations – taste, smell, feel – brings greater focus to the present.

Petting your cat/dog and focusing on the feeling of the fur.



YOU CAN PRACTICE ADDITIONAL SELF-COMPASSION TECHNIQUES BY VISITING THE FOLLOWING WEBSITE: WWW.SELF-COMPASSION.ORG



# PRACTICING SELF-COMPASSION

Think of the following examples, and how you could respond with self-compassion and understanding

You've been feeling unusually stressed lately, and even the thought of self-care doesn't feel tangible. You're mentally and emotionally strained because you are uncertain of what the next steps are for your loved one awaiting transplant and have taken on additional responsibility.

eg. It's tough when I want to prioritize my health but am overwhelmed with other responsibilities, but I know it is okay to feel this way. My body and mind are telling me it needs some rest, and I can be kind to myself by allowing it to do so. It's okay to be overwhelmed, but I'm going to focus on what I can do today, take some time for myself and do some stretches and deep breathing.

Some days you feel okay, but on other days you feel stressed and fatigued making it hard to feel motivated to focus on your own wellness. The burnout can be exhausting, and you're struggling with addressing self-care.

Write down a barrier that you anticipate. What strategy would you use to respond to this barrier in a helpful manner?

# MY NOTES

# **MY NOTES**

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#### **ACKNOWLEDGMENTS:**

This caregiving wellness manual was compiled and edited by Mandy McIntosh, with feedback from the TWP team and caregiving partners of the TWP. Funding was provided via a PURE summer studentship award (McIntosh and Culos-Reed, 2025).



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