

# Mental Health Caregiver Guide

A Guide for Caregivers of Persons Living with Mental Illness or Experiencing Mental Health Challenges





Canadian Mental Health Association Mental health for all Association canadienne pour la santé mentale La santé mentale pour tous



MICA Mental Illness Caregivers Association of Canada





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### **PROJECT LEADS**

This guide is a collaboration between Ottawa Public Health (OPH), Military Family Services (MFS), the Canadian Public Health Association (CPHA), the Canadian Mental Health Association (CMHA) Ottawa and National, and the Mental Illness Caregivers Association (MICA).

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# **HELP RIGHT NOW**

If you or the person you care for is in crisis and you need help right now, please:

- Call 911 (emergency) or your local emergency number
- Visit your local hospital's emergency department
- Contact a toll-free distress line in your province

We encourage you to seek out information on the mental health crisis and distress lines in your community - these are often available 24 hours a day / 7 days a week and have trained professionals that can help both you, the caregiver, and the person you care for with problem-solving, counselling, crisis support, and finding services.



# **PURPOSE OF THE MENTAL HEALTH CAREGIVER GUIDE**

This guide was created out of a need identified by a caregiver of a person living with severe mental illness and the president of the Mental Illness Caregivers Association (MICA). This caregiver reached out to Ottawa Public Health (OPH) to identify a gap in resources for caregivers of individuals living with mental illness or experiencing mental health challenges across the lifespan. OPH partnered with the national offices of the Canadian Mental Health Association (CMHA), the Canadian Public Health Association (CPHA) and Military Family Services (MFS) to develop a national resource for Canadian caregivers of children, youth, adults, and older adults facing these issues.

This guide is divided into two main sections: *Caring for YOU* and *Caring for the Individua*. The guide is further divided into Child, Youth, Adult, and Older Adult sections to reflect caring for individuals across the lifespan and the responsibilities associated with caregiving.

We encourage you to focus on the sections that are most helpful to you and the person you care for based on where you find yourselves on the journey to recovery.

This guide is intended to provide you, the caregiver, with helpful tips, tools, and information. We encourage you to "build your own toolbox" using the various Activities in this guide. These activities are designed to help you think about what you are learning in greater depth and to put some tools in place to help with your learning. Some information may seem simple or obvious, but it is a great starting point. The information is based on things you *can* control, and things that you *can* do to complement a treatment plan, promote recovery, or while waiting for services.

The information in this guide is based on information from trusted mental health providers including nurses, psychologists, psychiatrists, social workers, caregivers, and individuals with lived experience. We hope this guide will be helpful. We offer our strongest commitment and appreciation to caregivers and those they care for.



### **Public Health** Santé publique



MICA Mental Illness Caregivers Association



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# INTRODUCTION

The term "caregiver" includes all persons in a circle of care, including family members and other significant people who provide unpaid support to a person in need. In this guide they are referred to as "caregivers".

The term "individual", "person", "person you care for" or "loved one" refers to the person (child, youth, adult, or older adult) living with mental illness being supported by the caregiver. In this guide they are referred to as a "person" or "individual".

"Each person who steps up to the role of caregiver has to learn:

How to define the job such that it is one you CAN do;
How to do the job;

How to manage yourself such that you remain healthy and reliable.
For me, this was a process of discovery and development that took years.
There was no single place that I could turn to, so in many instances discovery took quite a while."

- John, caregiver

Caring for a person with mental illness or experiencing mental health challenges can be a difficult yet rewarding journey. This journey begins with the onset of mental illness as changes in the individual's behaviours, emotions, and thoughts are observed.

- Learning about the person's diagnosis can spark many different emotions in both you and in the person you care for. These emotions are often a mix of positive and negative feelings such as pride in learning new skills and knowing your efforts are appreciated, to shame and guilt.
- Learning about the person's particular illness and unique experience can help you as a caregiver to understand what is happening. It will also help you and the person you care for prepare for the journey to recovery.
- Being a caregiver means providing support for the individual and their unique journey by getting additional support, testing, diagnosis, care planning, treatment, recovery resources, and rehabilitation.

Each caregiver's experience is unique; from the person they care for to their specific responsibilities, no two caregivers are the same. Some caregivers provide continuous support for a family member who lives in their home, while others may help someone with occasional periods of mental distress. Whether you are providing long-term support or short-term care, your role is important and valued.

Mental Health Caregiver Guide | A Guide for Caregivers of Persons Living with Mental Illness or Experiencing Mental Health Challenges It is important to note that a caregiver may be affected by the individual's illness. Often, caregivers report going through a similar journey to that of the person they care for. When the individual is not doing well, some caregivers report that they also feel unwell (this can come out physically and/or emotionally). On the other hand, when the individual is doing well, the caregiver is often doing well too.

When thinking about your own mental health or the mental health of a loved one, it is important to recognize that good mental health is about living well and feeling capable despite challenges. People who live with mental illness can, and do, thrive just as people without a mental illness may experience poor mental health.

The purpose of this guide is to help you care for yourself and your own mental health while recognizing the responsibilities you have caring for someone else. You will find practical tips and positive coping strategies to add to your existing "toolbox". Use these tools to help support you and the person you care for along this journey.



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# **CARING FOR YOU SELF-CARE FOR THE CAREGIVER**

### **ABOUT THIS SECTION**

You will note that the first half of this guide is focused on caring for you. That's right, YOU! Keeping yourself healthy both physically and emotionally will allow you to be the best caregiver you can be.

Caring for YOU is divided into smaller sections.

Each section is followed by an Activity – the purpose of these activities is to help you build skills to add to your toolbox. Some of these helpful tools and tips may seem obvious but they are often overlooked when caring for someone else. You can use these skills as you journey through recovery with the person you care for.

"I had never really paid attention to the pre-flight information before, but after caring for a loved one with mental illness this past year, all of a sudden it struck a chord with me. The pre-flight recording reminded all passengers to put on their own oxygen mask first, before helping someone else put on theirs. I started crying as I realized I hadn't taken care of myself at all in the past year, and if I was to truly be there and support my loved one, I needed to take better care of me."

- Louise, caregiver



# **TAKING CARE OF YOU**

Taking care of a person living with mental illness or experiencing mental health challenges can be both rewarding and stressful. You will learn new skills and build a stronger relationship with the person you care for, though this time may be demanding as you take on new responsibilities. Stress is a natural part of life, but if not managed well, it can lead to your own health problems. Caregivers can have a tendency to focus on the person they care for more than themselves and put themselves as a second priority. The most important thing to remember as a caregiver is to take care of YOU. Actions we take to take care of our health and wellbeing are known as self-care.

Although being a caregiver entails advocacy for the individual, and lots of it, it's important for you to advocate for yourself and set boundaries. Just as in the pre-flight instructions, you should put on your own oxygen mask before helping another person put on theirs. Caregivers in the mental health context need to take care of themselves before they can take care of someone else.

### **COMMON BARRIERS TO SELF-CARE INCLUDE:**

Your own attitudes and beliefs: "I'm being selfish if I sleep in late today."

Being afraid of what you need: "I'm feeling over-worked, I need time off but can't take leave."

Being afraid or not knowing where or how to ask for help: "I don't want to bother them, they have their own problems."

Wanting to care and show your affections in a selfless way (common with family caregivers): "He's my son, he's my priority."

It takes courage to reach out to people and time to build trust. Building a support network is a very important part of self-care and good mental health.

Try to create a network of understanding and positive people who value your unique situation and are sensitive to your needs as well as the individual's needs. Support can come from family, friends, neighbours, colleagues, faith communities, clubs or even strangers in a support group. This will help you feel less alone and feel supported and empowered.

### **TIPS FOR TAKING CARE OF YOU**

- Set limits for yourself on what you can get done
- Say no if you need to: it is okay
- Ask for help: family, friends, even colleagues may want to help but may not know how to
- Delegate some of your responsibilities to others
- Take time to take care of yourself daily
- Prioritize your day
- Engage in activities you find relaxing (meditation, yoga, or a daily walk)
- Know your limits
- Learn how to recognize when you feel stressed
- Learn ways to cope with stress
- Talk to others who have been through what you are going through
- Share your feelings and thoughts with those close to you
- Maintain your other relationships ٠
- Try not to rely on caffeine, alcohol and drugs to cope
- Focus on things you can control
- Set realistic goals for yourself and the person you care for
- Be prepared so that if you need more support you will know who to turn to



**SKILL:** Connecting **TOOL:** Creating my support network

When thinking of a support network, what comes to mind? Who and what do you need? Who could help you with each need?

Keep in mind the various supports around you including:

- informal supports (friends, neighbours, family)
- formal supports (doctor, social worker, counsellor)
- unique supports (support group, faith or spiritual group)

### Looking at the table below, create a similar one for YOUR support network.

What I need?	Who?	How?
To vent to someone	My best friend	Over coffee or phone
Help with walking the dog	My neighbour's daughter	I will pay her \$7 a week
Respite	My mother-in-law	She will come over one Saturday per month
Cleaning	My other children	I will make a chore chart

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What I need?	Who?	How?

# SELF-CARE; A CRUCIAL PART OF CAREGIVING

Finding time for YOU when providing care for someone else can be challenging. In some cases, caregivers underestimate the toll that caregiving can take on their physical and mental health. Emotional and physical overload is an ongoing risk. Taking care of yourself and being mindful about your self-care is a great way to prevent burn out.

Understanding the time commitment and the physical and emotional stresses that are involved in caregiving will help you identify the need to make self-care a part of your daily routine. Time management is a crucial aspect of planning for self-care. Taking time every day to do something for you, or simply to reflect on your needs, will help you be better prepared to care for someone else.

Being a caregiver is a selfless job, focusing more on the needs of others than your own. It is important to find time in your day to stop and recognize the positives in your life - in your day, in the person you care for, in your job as a caregiver, and in yourself. Being mindful in your everyday life helps you to be self-aware. This means knowing how you are feeling both physically and mentally, as well as knowing your limits. Keeping positive and self-aware will help you stay healthy and realize when you are taking on too much and need help.

Remember, as a caregiver you are not alone. There are many people going through the same things you are who can help provide support and guidance. There are family organizations, peer support groups and mental health service providers that can provide you with information and tools to cope – all you need to do is reach out. You will find there are caregivers like you working hard to find answers to the challenges faced by their loved one and connecting with them will allow you to both share your experiences and learn from each other.

When you and the individual plan ahead, you will be better prepared if a crisis occurs. Part of planning ahead includes knowing where to look for resources when you need them most. You can make these plans while the person you care for is healthy, so they can add their ideas to the plan.

"There will be days that you want to give up, but if you didn't have these days you wouldn't appreciate the good ones... sometimes you need to ask for hope when you need it." - Susan, caregiver



**SKILL:** Making YOU a Priority **TOOL:** Connecting with myself and with others

Think of making YOU a priority as a coping skill to add to your toolbox. Do something that's just for you, focusing on you. This can be big or small: "I take time to read the paper in the morning by myself" or "I bought a plant for my office" or "I decided to re-connect with a friend".

Think of building meaning outside of caregiving: "I'm buying new strings for my guitar and taking up playing again," or "I take time to keep doing the activities I love".

Don't feel guilty or judge yourself if you feel you can't do something just for YOU. If this activity seems out of reach, make it smaller. Savouring the moment "just for you" can be as simple as turning up your favourite song on the radio or singing in the shower.

Day	What did I do just for me today?
Monday	I had coffee with my sister today
Tuesday	I had a relaxing bath today
Wednesday	I went for a walk to explore nature today





# **CAREGIVER'S BILL OF RIGHTS**

The following rights are reminders to take the time to take care of YOU. Read them when you need and add to them. Add rights that reflect your unique values, experiences and passions.

# I HAVE THE RIGHT TO:

- Connect with myself and my own unique experience as a caregiver. I acknowledge and confront my thoughts and behaviours when I can, but at times, I give myself permission to avoid these and do something fun and distracting.
- Take care of myself. This is not selfish. It will give me the energy to take better care of the person I care for.
- Get help from others even if the person I care for disagrees. I know my limits, and do only what I can do.
- Keep parts of my own life that do not include the person I care for. I have my own identity and my own life outside of caregiving.
- Do some things just for myself, whenever I want.
- Get angry, feel depressed, and talk about difficult feelings I experience. 6
- Get consideration, affection, forgiveness, and acceptance for what I do for the person I care for and don't let the person I care for control me by using guilt, anger or depression.
- Take pride in what I am doing. To be proud of the courage it has taken me to meet the needs of the 8 person I care for.
- 9 Make a life for myself that will help me ensure that I will continue to have a sense of purpose and happiness when the individual I care for no longer needs my help.
- **10** Expect and demand improvements in resources to help and support caregivers.
- **11** Add my own statements of rights to this list, based on my own unique situation, feelings and experiences.

### **BUILD YOUR** Activity: **OWN TOOLBOX**

**SKILL:** Exploring my Values **TOOL:** Reconnecting with my values and priorities

Identify an important value or priority in your life. Choose one that brings you happiness, gives you a sense of purpose, or helps guide you in your journey.

Define a goal that is related to this value/priority and outline small steps needed to meet your goal. Here are a few values to get you started:

- □ Acceptance
- □ Accessibility
- □ Autonomy
- Choice
- **Collaboration**
- Decision making
- Dignity
- Diversity
- **Evidence-informed**
- □ Knowledge
- **Fairness/equity**

### Value/Priority: <u>Respect</u>

# Goal:

### **Steps Needed:**

- Interrupt less
- Validate
- Listen more carefully
- Limit my judgements
- Take the Collaborative Problem Solving course



- Growth
- □ Health
- □ Honesty
- □ Inclusion
- **Independence**
- Personal Experience
- **Positivity**
- **Respect**
- Social networks
- **Spirituality**
- □ Support

**Improve** Communication



Value/Priority:	Goal:	
Steps Needed:		

Value/Priority:	Goal:	
Steps Needed:		

Value/Priority:	Goal:	
Steps Needed:		



# FEELINGS ABOUT CAREGIVING

Everyone's caring experience is unique to their situation, as are the feelings that go with it. As a caregiver, you may find yourself in sensitive situations that cause both positive and negative feelings – this is completely natural. It is important to remember that your emotions are sometimes out of your control, and "how you feel is how you feel". It is normal to have lots of different feelings and they are not right or wrong – they are your own. Let yourself feel your emotions and try to not judge them but rather accept them. Acceptance will let you confront these feelings and what they mean to you, how they affect your actions or even affect the individual you care for.

Long-term caregiver Maureen shares her thoughts:

"I think what would have helped me early on is knowing that it's okay to get angry about all the responsibilities. It is not necessarily okay to display your anger in certain ways. And it is okay to say no."

Below are some of the common experiences that caregivers feel.

## **NEGATIVE FEELINGS ABOUT CAREGIVING**

Caregivers face difficult situations and can sometimes have negative feelings about these situations. You may try to ignore these feelings by not letting yourself feel them or work through them. You may tell yourself that you should not feel a certain way or you may ignore your feelings.

But your feelings are your own; they are part of your unique experience and journey.

The negative feelings you may experience depend on your own situation. These are completely natural.

**ANXIETY:** Being unsure about the future can make you feel anxious. It can happen when you worry that something bad will happen. For example, you may feel anxious because you do not have enough help to cope with your current situation, which can lead you to think that things will not get better and might actually get worse.

**FEAR:** You experience fear when you feel threatened. The responsibilities of caregiving or what that includes may scare you.

**GUILT**: Some situations can cause you to feel guilt. For example, you could feel guilty because:

- you think that you are not doing enough
- you think that you do not have the energy to deal with one more day
- you are not able to keep promises you made to the individual you care for
- you have your own life outside the home while the person you are caring for might not.

FRUSTRATION, ANGER, AND RESENTMENT: These feelings often go together. You may be frustrated because you cannot find enough time for yourself and this may lead to anger and resentment.

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HURT: There may be days when you feel that no one appreciates what you are doing. For example, the individual may experience anger or frustration and may at times direct this towards you. It may be hard for you not to feel hurt or alone at these times.

ISOLATION: Sometimes you may not have the time to do things you like as often as you used to because of your caregiving responsibilities; this may lead to feeling all alone.

**GRIEF AND SADNESS:** Grieving is the process of adjusting to a loss. Grief can make you feel many emotions that are tough to understand. You could feel sad, angry, lonely, anxious and frustrated at the same time but also feel each of them separately at various times during the caregiving process.

### **POSITIVE FEELINGS ABOUT CAREGIVING**

Caring for a person can be a wonderful and positive experience. It can be full of laughter and close moments. You may get a lot of satisfaction from being able to help the person you care for when they need you most.

The positive feelings you have about being a caregiver depend on your own situation.

### **PERSONAL GROWTH**

You may feel that you are growing personally because you are learning skills, such as being more patient, that allow you to give the best care. At times, you may feel unsure how you or the person you care for will overcome a challenge – but you take things day by day or hour by hour and learn from it.

### **GREATER APPRECIATION FOR HEALTH AND WELL-BEING**

Caring for someone who is very ill can change the way you look at life and death. This may lead to a new understanding or deeper sense of the meaning of life; it may change what you see as important or change your personal goals.

### STRENGTHENED RELATIONSHIPS

Often the caregiving role helps you become much closer, physically and emotionally, to the person you are caring for and this can make you feel more appreciated. You learn that through hope and courage come strength. This helps form a trusting attachment to the person you care for.

> "I don't need to fill the silence, all I need to do is be there." - Mariam, caregiver

# **BUILD YOUR** Activity: **OWN TOOLBOX**

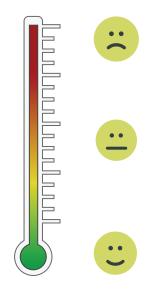
**SKILL:** Personal Reflection **TOOL:** Taking your emotional temperature

Taking your emotional temperature means reflecting on "where you're at".

### **REFLECTION:**

What am I feeling emotionally? Where am I feeling it in my body? What helps me feel more positive? What makes me feel more negative? Looking at my day, what went well? Looking at my day, what could have gone better? What would help me right now?





	-	



### **REFLECTION:**

What am I feeling emotionally? Where am I feeling it in my body? What helps me feel more positive? What makes me feel more negative? Looking at my day, what went well? Looking at my day, what could have gone better? What would help me right now?

# RESILIENCY

Resiliency is a person's ability to cope well with adversity – your ability to keep going and adapt to changes as they come. Life's ups and downs.

People who are resilient are healthier, live longer, have less depression, are happier in relationships, and are more successful in their personal and professional lives. Resilient thinking can be learned – this is good news.

One of the key ways is to practice accurate and flexible thinking. What does that mean? Looking at the facts and what you know and being able to go along with things as they come. Learning about yourself and where you're at is an important first step to developing resiliency.

Resiliency is important for caregivers. Caregivers cannot be at their best every day - no one can. When you are faced with a challenge resiliency helps you through it. The individual you care for will look to you at times for resilience; this is a great opportunity to show them how by setting a good example for them. There are four important areas of resiliency you can focus on as a caregiver:

### **RELATIONSHIPS**

- Supportive
- Positive
- Sharing and caring
- Helpful and offer problem-solving
- Fun.

### **EMOTIONAL SKILLS**

- Calming yourself and self soothing
- Controlling your anger and frustration
- Reminding yourself that bad feelings will pass
- Avoiding decision-making when upset.

### COMPETENCE (THINKING ABILITY)

- Trying to understand your problems before solving them
- Finding answers to help in your role of caregiving
- Controlling what you can
- Accepting the things you cannot control.

### **BEING HOPEFUL (OPTIMISM)**

- Finding hope during hard times
- Finding ways to help ourselves
- Making the most out of the little positives
- Having a positive, supportive person in your network.





**SKILL:** Checking In – Self-awareness **TOOL:** How resilient am I?

Resiliency is the ability to "bounce back" from a difficult time or weather the storm.

Being able to check off "agree" to most of the boxes means you have the ability to build resiliency in your life. Do not feel frustrated if you have many "disagree" boxes. Build on your strengths and come back to the checklist in a few weeks. This shows you are starting to build resiliency.

Resilience Quiz	Agree	Disagree
When life gets tough, I reach out to friends and family	$\bigcirc$	$\bigcirc$
I believe that I can learn from difficult times	$\bigcirc$	$\bigcirc$
When I am under stress, I still try to lead a normal life	$\bigcirc$	$\bigcirc$
When life gets busy or stressful, I still take time for myself	$\bigcirc$	$\bigcirc$
I have a great support network	$\bigcirc$	$\bigcirc$
After a stressful event, I can let go and move forward	$\bigcirc$	$\bigcirc$
I cope well with change		$\bigcirc$
I try to live in the moment and appreciate the good things in life		$\bigcirc$

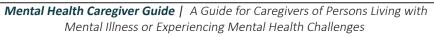
# **SCORING**

Agree: If you answered Agree to 5 or more of the statements, your resilience is good. The higher the number of Agrees, the more resilient you are and feel that even though life can have tough times, it is important to keep your perspective.

Disagree: If you answered Disagree to 5 or more of the statements, your resilience may be low. The higher the number of Disagrees, the less resilient you are at this time. Start working on a plan to improve your resilience. See the next section Reflection for some ideas.

### **REFLECTION:**

When faced with a challenge, how will I recover from it? What helped me bounce back or get through a difficult time in the past? Can I think back to a time when I coped well with a tough time in my life? What tools and supports do I have in my life that can help build resilience?





# OWN TOOLBOX

### **REFLECTION:**

When faced with a challenge, how will I recover from it? What helped me bounce back or get through a difficult time in the past? Can I think back to a time when I coped well with a tough time in my life? What tools and supports do I have in my life that can help build resilience?

# **RECOGNIZING WHEN YOU NEED HELP**

## **PHYSICAL LIMITATIONS**

You may have health problems that make it harder to be a caregiver. For example, if you have issues with eyesight, you may find it difficult to read medication bottles. The physical stress of caregiving can also affect your health, making a breathing problem worse. If you have trouble with your bones and joints, you might not be able to care for another person at all.

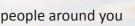
If you have pre-existing health conditions, you may need extra help with your caregiving duties. For example, if you cannot hear or see very well, you may need help. There could be a risk to the one you care for if you misunderstand a health care provider's instructions, or if you cannot hear the person call out for help. It is important to have regular contact with your health care provider to maintain your own physical and emotional health. Be open and honest about any changes in your health as a result of caregiving.

### SIGNS YOU MAY NEED HELP COULD INCLUDE:

- Pain that seems to have no physical cause
- Headaches •
- Stomach problems
- Inability to sleep or poor sleep ٠
- Teeth grinding
- Tense muscles
- Problems with alcohol use or drug use
- No interest or awareness of the world and the people around you •
- Strong emotions and mood swings
- Forgetting things
- Inability to relax
- Changes in eating habits
- No energy
- Inability to concentrate
- Existing health problems getting worse
- Decreased or lack of sex drive
- Feeling depressed



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## **EMOTIONAL LIMITATIONS**

The stress of your added responsibilities as a caregiver and the feelings that go along with it can be very difficult. It is possible to become so overwhelmed that you cannot give the best care. This does not mean that you are a bad caregiver. It just means that you have reached your limit. At this point it is important to ask for help.

### HERE ARE SOME REASONS WHY CAREGIVERS DO NOT ASK FOR HELP:

- Feelings of guilt and shame
- Not knowing that others are in the same situation
- Lack of knowledge about available options/resources •
- Not being able to pay for formal caregiving services
- Not enough time to find help
- Cultural beliefs that discourage help from outside the family
- Lack of services to meet your needs
- Feelings of depression, which can reduce the motivation needed to find help
- Not being able to talk about feelings. ٠

It is always okay to ask for help. Asking for help is part of providing the best care possible. Many caregivers share this advice:

### "Do not be afraid to ask for the help you need!"

You should feel proud of what you are able to do and realize that you have a right to continue to maintain good physical and mental health, and to take time to do things other than caregiving that make life meaningful life for you.

If you notice a big change in your mental or physical health, speak to your health care provider about it as soon as you can. Several distress lines offer support to caregivers, do not hesitate to reach out.

"I feel guilty taking time for myself, what helped was remembering that I'm a person too with needs and with limits."

- Pierre, caregiver



**SKILL:** Mindful Breathing **TOOL:** Helping to control emotions

### MINDFUL BREATHING

- 1. Get settled and comfortable. It's best if you sit with your back straight and shoulders down.
- back as soon as you notice. Don't criticize yourself.
- 4. did you notice?

	Mindful	
Day	Done?	
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		



2. Breathe in and out comfortably. As you breathe in, mentally count "one". As you breathe out, mentally count "two". Go all the way up to 10, and back down again. When your mind drifts, just gently bring it

3. If you totally lose track, just start again from the first step. Easy. Don't criticize yourself. Just observe. Record your experiences below. What did you notice about mindful breathing? Was it easy? Hard? What

Breathing	
	What was it like?

# WHAT TYPE OF HELP DO YOU NEED?

Figuring out what type of help you need is very important. Explain your situation to family, friends, colleagues, and community members so that they are able to understand your situation and support you. Give them regular updates and try to include them in any decisions you want to make.

You may need help to take some time for yourself – maybe even a short vacation. Ask a family member or friend to take your place and be there if the person you care for needs support during your time away. Think about what you can and cannot do on a regular basis. Then think about how often you need help. Is it every day, once a week or in the evenings? Make a list of people who have agreed to help out when you need a break.

### FAMILY, FRIENDS AND NEIGHBOURS:

The people closest to you and your situation may be a source of help that will not cost money. Ask them for help and be specific. When many people are helping, each person might only need to offer a small amount of time.

Even though meetings and discussions with family and friends are helpful, make sure to respect everyone's opinions and limits.

### **PEOPLE CAN HELP BY:**

- Walking the dog
- Preparing meals in advance
- Running errands
- Helping you take care of your own household and family
- Taking the individual to appointments or facilitating transport
- Providing friendship and support to you, the caregiver.

A neighbour may be able to help with shovelling snow or mowing the lawn or can be on standby for the individual in case of an emergency. Even family or friends who live far away can help by offering friendship and support over telephone, mail, or email communication.

When asking for help, think about the skills and strengths people around you have and take advantage of these by asking them to help you with something they are familiar with or feel confident taking on. At times you may have to teach someone how to best help too.

### **SUPPORT GROUPS:**

People who are dealing with similar caregiving challenges may find a support group helpful. Members of a support group share their feelings and talk about what they are going through in a safe and accepting environment. You can find out about community resources, get tips on caregiving and just feel better about your situation by being with people who understand what you are going through. There are general support groups for caregivers as well as ones that focus on a specific illness or condition.

### MAKE SURE THE SUPPORT GROUP IS RIGHT FOR YOU BY ASKING YOURSELF:

- Does it make you feel welcome and safe?
- Is everything you share kept confidential?
- Is the environment respectful?
- Are meeting times and places good for you? ٠
- Are experienced health care providers involved?
- Does the group invite experts to speak?

Reach out to your community, including faith, spiritual and cultural groups. They might have a support network you can join. You can also get help from a professional counsellor to manage conflict, stress, grief, anger and other feelings.

To find out more information about support groups in your area, call 211 if available, or talk to your health care provider. You can contact groups focused on a particular topic or even find a support group online. You can also look at local community listings to find other sources of support. Try looking under headings such as Home Health Care Services, Supplies, Charitable and Not-for-Profit Organizations.

Your province or territory may have an association for caregivers and caregiver support. Try searching for links on your Ministry of Health's website, or on the Health Canada website.

### **MEDICAL HELP:**

Sometimes no matter what you do, you still feel stressed or sad. If you continue to feel this way, it is important that you speak to your health care provider as soon as possible. Remember that you need to take care of YOU first.

You can also reach out to a service such as the Canadian Mental Health Association (CMHA) to help you find additional support with caregiving responsibilities. Click here to find your local CMHA. Other great resources for support can include health-information phone lines, distress lines (by province/ territory), and medical walk-in clinics (including mental health walk-in counselling clinics) - search your local listings or online for one in your area.

### TIPS:

- Learn to recognize when you need to ask for help
- Do not feel guilty or if you need to ask for help •
- Work with other family members, including your loved one, to decide on the best solution ٠
- Congratulate yourself regularly for all you have been able to do!



**SKILL:** Getting the Help I Need **TOOL:** Creating a plan

Create a checklist of possible supports – people who you could include in your support network to help you and the person you care for. Think about how you could reach out and why this would be helpful.

The more complete the table, the more options and supports you will have when you need them.

Who?	For what?	How?
Family doctor	Letter to be excused from work	Call doctor's office to schedule an appointment

Who?	For what?	How?

Who?	For what?	How?

V	Nho?	For what?	How?

Who?	For what?	How?

l	Who?	For what?	How?

Who?	For what?	How?

WHAT IS CAREGIVER BURNOUT?

Being resilient when faced with the stress associated with caregiving helps prevent burnout. However, no matter what your coping style, too many responsibilities and too much stress can lead to burnout. Burnout means that you cannot keep giving the best care to the individual because you are worn out emotionally and/or physically. It means it's time to check in and make some changes.

### HERE ARE SOME QUESTIONS TO HELP YOU SEE IF YOU ARE AT RISK FOR CAREGIVER BURNOUT:

- Do you feel like you are being pulled in different directions?
- Do you feel like you are trapped in your role as a caregiver? ٠
- Is there a problem between you and the people you are close to, between you and the one you care for, or between the people you are close to and the one you care for?
- Do you feel that you are not getting help from other people? •
- Is the person you care for demanding and expecting too much from you? •
- Do you feel like you cannot do everything that your loved one wants and expects? ٠
- Do you have a hard time talking to others around you?
- Is your health or the health of the one you care for getting worse? •
- Do you feel like there is too much to do?

If you said yes to any of the questions above, you may be at risk of caregiver burnout. It's important to take care of yourself and make your health a priority. Speak to a health care provider such as a family doctor, nurse practitioner or mental health provider as they know you and your unique situation best. If you are currently working, you may also have Employee Assistance Programs (EAP) through your workplace; contact your human resources department for more information. Lastly, distress or crisis lines and walk-in mental health counselling services might be helpful. These can be found in a number of communities.

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**SKILL:** Preventing Burnout **TOOL:** Creating a plan

It's very important to create a plan before burnout happens.

Hopefully, you will never have to use this plan, but if you do, it will be helpful to have it already completed so that you can refer to it and follow the steps you identified.

Consider this:

- 1) Who will be in the plan? Your health care provider, peer support groups, mental health agencies, friends and family.
- 2) For what tasks? For your own physical or mental health. For peer support. For comfort.
- 3) How? What are the steps needed to reach the "who" and "what"?
- 4) Which activities will help? List all that come to mind.

List as many people and services as possible, using the *Resource Guide – Greater Ottawa* or the *Toolbox for Identifying Resources in Your Region* adapted to your area and fill in the table.

Add your personal activities that help, such as spending time with friends and family and anything else you enjoy and that helps you get through hard times. For some, going to see a movie, a comedy show or a play may be very helpful, while going for a walk or spending time alone may be helpful for others. The more you have listed in the table, the more helpful it will be at times when you are feeling overwhelmed.

Who?	For what?	How?	Activities that can help prevent burnout?
Family doctor	Letter to be excused from work	Call doctor's office to schedule an appointment	- Walking the dog - Going to yoga - Getting enough sleep



Who?

For what?



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How?	Activities that can help prevent burnout?

# **CARING FOR THE INDIVIDUAL**

### **ABOUT THIS SECTION**

### INTRODUCTION TO THE STAYING S-T-R-O-N-G STRATEGY

A Staying STRONG approach will reduce vulnerability and increase resiliency for both the caregiver and the person they care for. Healthy habits are an important part of managing mood, anxiety, depression, anger, irritability, and other aspects of mental health. The Staying STRONG strategy is adapted from Dialectical Behaviour Therapy (DBT) and informed by public health. Don't worry if this doesn't sound familiar.

What's important is that the Staying STRONG strategy focuses on skills that are within reach and easy to put into action. These skills are intended to give the caregiver and the individual control over the things that they can control and empower them, especially in instances where an individual is waiting for services and feels powerless.

The Staying STRONG skills focus on a holistic approach and challenge caregivers and individuals to focus on very important factors that contribute to good mental health. These skills can be used in many different areas that foster mental health.

### **CAREGIVER RESPONSIBILITIES**

It may feel like you have a long list of responsibilities as a caregiver, but you do not have to do it alone. Asking for help is always OK. When caring for a person of any age, open and clear communication is essential. Speaking calmly and being aware of your body language will help to avoid conflict and build trust and comfort between you.

You can build strong trust and communication between you and the person you care for by including them in planning their care. This allows them to practice decision-making and problem-solving, which helps them feel more independent and confident. Maintain good, open communication so that the individual feels comfortable sharing their concerns with you. As their needs change or when they have questions about their care they will feel they can come to you with them. When they approach you it is important to be patient and listen carefully. Working together through this experience will help build a partnership and ensure that the person receives the care they need.

Having regular communication with others who are directly involved in the individual's care plan is also necessary to make sure that the individual gets what they need. For example, talking with teachers of children and youth with mental illness about new concerns can help make sure that they are properly cared for in the various aspects of their lives. Keep open communication with other family members so that they know how they can help you in your caregiver role.

Try to share some of your caregiver responsibilities. Setting realistic expectations of how much you can do is important in preventing emotional overload or burnout. It is easy to find yourself taking on more than you can maintain. At any point during your role as a caregiver (ideally when you first take on this role), write down what is expected of you. It's easy to take on a little extra here and there, which can add up to something you cannot maintain.

When planning care you will need to think of the person's mental, physical and home safety needs, among other things. The next section will help you in this planning process.

# **STAYING STRONG: CHILDREN**

As a caregiver, Staying Strong may not always feel possible. But by following as many of the Staying Strong points below, you are giving yourself and the child you are caring for their greatest chance to be healthy and resilient. Check off as many of the six steps below that you can do today. Don't be frustrated about the ones you cannot do right now. Try each day to get closer to achieving that step.

## HOW CAREGIVERS CAN STAY STRONG

### LEEP Follow a routine - Have a good balance between rest and activities Make sleep hygiene important - Role model good behaviour for the child you care for **AKE CARE OF YOUR HEALTH** - In order to care for someone else you have - Do not push yourself to burnout - Have a back-up caregiver or respite in case you to stay healthy - Know your limits become sick and need time off - Practice self-care **ELATIONSHIPS** - Think of your relationship with the child you - How are you maintaining validation and care for: what is working well? What could be attachment in your relationship? Does anxiety or improved? fear get in the way of you being the caregiver you





### WN IT



control of your life;

- Something that's just for you;

## UTRITION



food gives you energy: don't run on empty

- Model good behaviour for the child you care for and educate them about healthy eating and food choices

## **ET MOVING**

Ensure that you maintain leisure and activity Incorporate physical activity such as an evening or morning walk into your everyday life

### Once a day do something that makes you feel in - That you're good at, that's positive - this will give you a sense of mastery and accomplishment.

want to be?

## Eat a balanced diet, not too much, not too little, - Try to make eating together a regular activity, buying groceries and meal preparation are also activities you can do together

### - Get involved with social activities and organized sports

# HOW CHILDREN CAN STAY STRONG



## LEEP

Have child keep a bedtime routine Limit technology-use before bed



## **AKING MEDICATIONS**

- CHILDREN CANNOT TAKE MEDICATIONS ON THEIR OWN



## **ELATIONSHIPS**

Help the child maintain positive and supportive relationships

Gain support from child care providers or school officials so that the child is constantly surrounded by a trusting adult they can confide in

- Make sleep hygiene important

- Give medication as prescribed

and activities

- Teach the child how to communicate what they are feeling

- Help them maintain a good balance between rest

- Monitor how well medication is working and any side effects - report these to health care provider

- Maintain the warmth in your relationship with the child
- Make times for snuggles and cuddling



# WN IT

### Once a day have the child do something that they feel confident doing

- Put a sticker on a calendar for each day they do this
- This provides a sense of mastery and will make them feel positive and increase their self-esteem



## JTRITION

Have the child eat a balanced diet made of healthy and nutrient-dense foods;

- Not too much, not too little: food is fuel - Don't have the child run on empty



## ET MOVING

Engage the child in activities outside in nature

- Encourage walking, exercise, extra-curricular activities, and sports

# **CAREGIVER RESPONSIBILITIES – CHILD**

Below is a listing of the major caregiver responsibilities for a child living with mental illness or experiencing mental health challenges. Depending on where you're at in the caregiver journey, this may feel like a long list, but focusing in on these key responsibilities will help you provide the best care, and help the individual feel supported on their road to wellness and recovery.



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# **STAYING STRONG: YOUTH**

As a caregiver, Staying Strong may not always feel possible. By following as many of the Staying Strong points below as you can, you are giving yourself and the youth you care for the greatest chance to be healthy and resilient. Check off as many of the six steps below that you can do today. Don't be frustrated about the ones you cannot do right now. Try each day to get closer to achieving that step.

for

# HOW CAREGIVERS CAN STAY STRONG

## LEEP

- Keep a routine
- Make sleep hygiene important
- Limit technology-use
- AKE CARE OF YOUR HEALTH - In order to care for someone else you have to
- stay healthy - Know your limits
- Practice self-care



# ELATIONSHIPS

- Think of your relationship with the youth you care for:
- What is working well?
- What could be improved?
- **ΛΝ ΙΤ**
- Once a day do something that makes you feel in control of your life; - Something that's for you;
- That you're good at, that's positive;

- Have a good balance between rest and activities

- Do not push yourself until you are so ill that you

Does anxiety or fear get in the way of you being

- Have a back-up caregiver in mind in case you

can no longer care for someone else

- How are you maintaining validation and

attachment in your relationship?

the caregiver you want to be?

activity you do together

sports

become sick and need time off

- Model good behaviour for the youth you care

- This will give you a sense of mastery and accomplishment.



## UTRITION

- Eat a balanced diet;
- Not too much, not too little;
- Food is fuel -- don't run on empty.
- Model good behaviour for the youth you care for and educate them about healthy eating and food choices



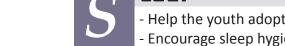
## ET MOVING

Make sure that you maintain leisure and activity - Try something like morning or evening walks, Incorporate physical activity into everyday life

get involved with social activities and organized

- Try to make eating together a regular activity

and make groceries and meal preparation an



LEEP

- Help the youth adopt a bedtime routine Encourage sleep hygiene, educate the yo about the importance of maintaining a g balance between rest and activity

## **AKING MEDICATIONS**

- Ensure that the youth is taking medication prescribed;
- Have them tell their doctor how it's wor them:
- Make sure they know their rights;



## **ESIST**

Help the youth resist urges Avoid negative behaviours



Once a day encourage the youth to do something that makes them feel in control their life



## UTRITION

Encourage the youth to eat a balanced d Not too much, not too little;



## ET MOVING

- Ensure that the youth maintains leisure a activity
- Encourage them to incorporate physical into their everyday life by getting outdoo walking to their destinations

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# HOW YOUTH CAN STAY STRONG

outh good	- Rest is important to recovery
ion as rking for	<ul> <li>Monitor and report side effects, and are aware of the harmful interactions between drugs and alcohol and their medications;</li> <li>Have them talk to their doctor or someone they trust.</li> </ul>
	<ul> <li>Negative behaviours can include people, social media, technology, drugs, and alcohol</li> </ul>
ol of	<ul> <li>Something that's for them, that they're good at, that's positive – this will give them a sense of mastery and accomplishment</li> </ul>
liet;	- Food is fuel don't run on empty.
and activity ors and	<ul> <li>Encourage them to get involved with social activities and organized sports</li> </ul>

# **CAREGIVER RESPONSIBILITIES – YOUTH**

Below is a listing of the major caregiver responsibilities for a youth living with mental illness or experiencing mental health challenges. Depending on where you're at in the caregiver journey, this may feel like a long list, but by focusing in on these key responsibilities it will help you provide the best care, and will help the individual feel supported on their road to wellness and recovery.



# **STAYING STRONG: ADULTS**

As a caregiver, Staying Strong may not always feel possible. But by following as many of the Staying Strong points below as possible, you are giving yourself and the adult you are caring for the greatest chance to be healthy and resilient. Check off as many of the six steps below that you can do today. Don't be frustrated about the ones you cannot do right now. Try each day to get closer to achieving that step.

# HOW CAREGIVERS CAN STAY STR

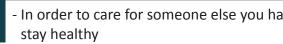
### LEEP



Keep a routine, make sleep hygiene impo

Have a good balance between rest and a

## AKE CARE OF YOUR HE



- Know your limits - practice self-care

## **ELATIONSHIPS**

- Think of your relationship with the adult care for:
- What is working well?
- What could be improved?

## 



- Once a day do something that makes yo control of your life:
- Something that's for you;

## UTRITION

- Eat a balanced diet:
- Not too much, not too little;
- Food is fuel don't run on empty.
- Model good behaviour for the adult you

# **ET MOVING**

- Incorporate physical activity in everyday
- Try to make time for leisure and daily ac

TAY S	STRONG
ortant activities	<ul> <li>Model good behaviour for the adult you care for</li> </ul>
EALTH	
	<ul> <li>Do not push yourself until you are so ill that you can no longer care for someone else</li> <li>Have a back-up caregiver in mind in case you become sick and need time off</li> </ul>
t you	<ul> <li>How are you maintaining validation and attachment in your relationship?</li> <li>Does anxiety or fear get in the way of you being the caregiver you want to be?</li> </ul>
ou feel in	<ul> <li>That you're good at;</li> <li>That's positive – this will give you a sense of mastery and accomplishment.</li> </ul>
ı care for	<ul> <li>Try to make eating together a regular activity</li> <li>Use grocery shopping</li> <li>Meal preparation and cooking as an activity and opportunity to connect</li> </ul>
ctivity / life	<ul> <li>Such as a morning or evening walk get involved with social activities and organized sports</li> </ul>

# HOW ADULTS CAN STAY STRONG



## LEEP

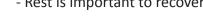
Help the adult adopt a bedtime routine Make sleep hygiene important

- Educate them on the importance of having a good balance between rest and activities - Rest is important to recovery

mindful of the effects of drugs and alcohol on

medications - have them talk to their doctor or

- Monitor and report side effects, and are



someone they trust.



## AKING MEDICATIONS

- Remind the adult to take medication as prescribed
- Have them tell their doctor how it's working for them
- Ensure that the adult knows their rights, and:



## **ESIST**

Help the adult resist urges

- Avoid negative behaviours, drugs, and alcohol



# WN IT

Once a day encourage the adult to do something that makes them feel in control of their life:

- Something that's for them, that they're good at that's positive – this will give them a sense of mastery and accomplishment



## UTRITION

Encourage the adult to eat a balanced diet Not too much, not too little;

- Food is fuel - don't run on empty.



## ET MOVING

Ensure the adult maintains leisure and activity Encourage them to incorporate physical activity into their everyday life by getting outdoors and walking to their destinations

- Encourage them to get involved with social activities, groups or organized sports

# **CAREGIVER RESPONSIBILITIES – ADULT**

Below is a listing of the major caregiver responsibilities for an adult living with mental illness or experiencing mental health challenges. Depending on where you're at in the caregiver journey, this may seem like a long list, but by focusing in on these key responsibilities it will help you provide the best care, and will help the individual feel supported on their road to wellness and recovery.



- companionship
- validation
- encouraging independence
- managing problematic
- educating others about
- seeking out community

- providing coordination of

- meal planning and preparation
- food safety

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impacting them - you will want to make sure

they are supported as well. Even infants and

young children are affected by stress in a home environment; it can affect their social and emotional development.

# **STAYING STRONG: OLDER ADULTS**

As a caregiver, Staying Strong may not always feel possible. But by following as many of the Staying Strong points below, you are giving yourself and the older adult you care for the greatest chance to be healthy and resilient. Check off as many of the six steps below that you can do today. Don't be frustrated by the ones you cannot do. Try each day to get closer to achieving that step.

# HOW CAREGIVERS CAN STAY STRONG

## LEEP

Keep a routine Make sleep hygiene important - Have a good balance between rest and activities

- Do not push yourself until you are so ill that you

- Have a back-up caregiver in mind in case you

- Model good behaviour for the older adult you care for

- AKING CARE OF YOUR HEALTH - In order to care for someone else you have to
  - stay healthy - Know your limits
  - Practice self-care

## **ELATIONSHIPS**

- Think of your relationship with the older adult you care for, what is working well? - What could be improved?
- How are you maintaining validation and attachment in your relationship?

can no longer care for someone else

become ill and need time off

 Does anxiety or fear get in the way of you being the caregiver you want to be?



# **WN IT**

for

control of your life: - Something that's for you;

Once a day do something that makes you feel in - That you're good at, that's positive; - This will give you a sense of mastery and accomplishment.



## UTRITION

- Eat a balanced diet, not too much, not too little, Use grocery shopping, meal preparation, and food is fuel; don't run on empty, - Model good behaviour for the person you care
  - cooking as an activity and opportunity to connect



## LEEP



- Help the older adult adopt a bedtime ro - Make sleep hygiene important

## **AKING MEDICATIONS**

- Remind the older adult to take medicati prescribed
- Have them tell their doctor how it's wor them
- Ensure that they know their rights:

## **ELATIONSHIPS**



- Help the older adult find comfort in companionship
- Tell them to let others know that they needed. company
- Help them get involved in their commun

## WN IT

- Once a day encourage the older adult to something that makes them feel in cont their life:
- Something that's for them;

## UTRITION

Encourage the older adult to eat a balar As their appetite decreases it's importar they eat nutrient-dense foods

## ET MOVING

- Encourage walking;
  - Stretching;
  - Range of motion exercises;

- Try to make eating together a regular activity



## **ET MOVING**

- Ensure that you maintain leisure and activity Incorporate physical activity into everyday life like morning or evening walks
- Get involved with social activities and organized
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sports

outine	<ul> <li>Educate them on the importance of having a good balance between rest and activities</li> <li>Rest is important to recovery</li> </ul>
on as <sup>.</sup> king for	<ul> <li>Monitor and report side effects;</li> <li>Are mindful of the effects of drugs and alcohol on medications;</li> <li>Have them talk to their doctor or someone they trust.</li> </ul>
eed iity	<ul> <li>Ensure that they do not isolate themselves</li> <li>Encourage them to let loved ones know how they're feeling and what they need from their relationships</li> </ul>
do rol of	<ul> <li>That they're good at, that's positive;</li> <li>This will give them a sense of mastery and accomplishment.</li> </ul>
nced diet nt that	<ul> <li>Ensure that they don't eat too little, food is fuel: don't run on empty</li> </ul>
	<ul> <li>Physiotherapy, and;</li> <li>Water activities like swimming, and low impact activities.</li> </ul>

# **CAREGIVER RESPONSIBILITIES – OLDER ADULT**

Below is a listing of the major caregiver responsibilities for an older adult living with mental illness or experiencing mental health challenges. Depending on where you're at in the caregiver journey, this may feel like a long list, but focusing in on these key responsibilities will help you provide the best care and will help the individual feel supported on their road to wellness and recovery.



# CONCLUSION

We hope this guide provided you with helpful tips and information and your "toolbox" contains a few more supports, resources, and coping tools. We encourage you to complete the Activities in this guide often and continue to build on these. We also encourage you to Stay Strong and encourage your loved one to do the same.

Remember that some of this information may seem simple, or obvious, but it is a great starting point. The information in this guide is based on things you can control, and things that you can do to complement a treatment plan, promote recovery, or while waiting for services.

Caring for a person with mental illness or someone experiencing mental health challenges can be a difficult journey, we hope that this guide has challenged you to think about on your own unique journey and given you tools to advocate for not only yourself, as a caregiver, but also for the individual you care for. As you support the individual throughout their journey to recovery, we urge you to ensure you maintain your own emotional and physical wellbeing. As a caregiver, you are faced with several responsibilities – one of these is self-care. Taking care of YOU!

Remember that you are not alone. Others are going through this as well. Reach out, enhance your support network, find peers, and remember to stay strong.

"I'm so thankful to have you by my side supporting me along this journey. With you, I feel I can conquer the peaks and the valleys ahead. Together, we'll stay strong and resilient. It won't always be easy, it may get hectic and stressful, but with you caring for me and I caring for you, we'll make it through." - The Individual in all of us



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