

## section 3: caring for the caregiver

Caregivers put a lot of energy into caring for and supporting a relative with mental illness. They often work tirelessly, despite being treated badly at times, and perhaps with no apparent appreciation. Yet they continue to express ongoing care and love for the person.

In this section, we are asking you to turn some of the care and love towards yourself and to commit to doing things that you really enjoy, that you find relaxing, or that simply offer a distraction from your daily life. We are asking you to give yourself a break. You deserve it!

### Healthy Altruism

Care of self is as important as care of your ill relative, particularly if they will be living with you. Caregiver role-overload can lead to stress and illness in the caregiver. In order to avoid this, we strongly recommend you adopt an attitude of healthy altruism rather than one of total sacrifice. Healthy altruism means being vigilant about your own needs, the needs of other well family members, as well as the needs of your ill relative.

### Healthy Boundaries

Part of taking care of yourself is to be able to put some distance between you, the caregiver, and your ill relative on a regular basis.

Boundaries need to be established for your protection. Caregivers can easily find themselves enmeshed with their ill relative and the illness. Identities easily become porous rather than well-defined, with the wishes and needs of the ill relative becoming the wishes and needs of the care-giver.

Boundaries need to be developed regarding how much time is spent doing for and thinking about the ill relative. Careful attention needs to be paid to prevent involvement from becoming all-consuming. The result for the caregiver can be isolation, burn-out, depression, or ill health.

Although an intense level of involvement may be necessary when the crisis is recent and the ill relative's needs are urgent, problems can arise if this level of involvement is allowed to persist.

### Responding to Progress

Along the recovery journey the caregiver's role should gradually transition from *helping* to *supporting*. The following suggestions may aid in this transition:

- Try to avoid becoming stuck in "illness talk" and gradually reduce the amount of conversation revolving around your relative's illness.

In the event of an emergency, first put your mask on yourself and then attend to that of your loved one.

#### Caregiver

Identity  
Health  
Wishes  
Needs

#### Boundaries

#### Relative

Identity  
Health  
Wishes  
Needs

- Try to be alert to the changes and take advantage of them to broaden the opportunity for variety of activity and task allocation for yourself and your relative.
- As your relative begins to feel better they will likely need less of your help. Look at the ways in which you currently provide help and how you might begin shifting from helping to supporting;
- Allow your ill relative to exercise choices and make decisions about their life. Support them to make good decisions rather than making the decision for them. While “rescuing” may be needed in times of crisis, this does not encourage empowerment and may make it difficult for your relative to learn to stand on their own two feet.

Please refer to Section 6: Transitioning Away from Mental Illness and Section 1: Essential Ingredients for Recovery for more information on how to respond to progress.

### Survival Techniques

Continue to communicate with the professionals involved in your family member’s care. Work towards an atmosphere and philosophy of collaboration. Be respectful and expect the same in return.

Reach out to family, extended family, and friends. Remember, though, it may take time for some people to understand this situation. Look to family and friends who aren’t afraid to support you. Do not isolate yourself but rather build a support system to help you problem-solve and learn about ways to navigate the mental health system.

Getting well often takes time, and patience is needed. Encourage your family member to spend time doing enjoyable activities but keep in mind this may be difficult for them to do at first.

Consider personal counselling, grief counselling, marital counselling, or family counselling if you are feeling overwhelmed. Check to see if you can get these through your mental health team, your extended health benefits, or privately if you can afford them.

“Not only is it better for the sick to be left alone at times, it is also better for the well to leave them at times. Healthy people can be contaminated by the gloom and depression of the ailing if they come too close or have too much sympathy”

*The Alchemy of Illness, Kat Duff, 1993.*

If one of the goals is for your relative to live independently, find out how they can be put on every housing list possible. Information is available through mental health centres, the Canadian Mental Health Association or

Mental illness is a difficult thing for some people to make sense of, so you may want to be selective and begin with people you know will be supportive. Be respectful of your family member’s need for privacy.

other non-profit community organizations. Work with your relative to determine what type of housing would meet their needs and preferences.

Monitor your own emotional state. Seek balance and serenity. Uncertainty can foster fear, anxiety, or apprehension. These feelings are harmful to yourself and unhelpful to the ill family member.

## Taking Care Of You

Although we are constantly exposed to inspirational messages in greeting cards, well-meaning e-mails, advertisements, and so on, in times of crises there may be one that really “sticks” and takes on a particular significance to you. It can act as the guidepost you need to get through the tough times you are facing.

Consider the following words of inspiration:

“It is not easy to find happiness in ourselves, and it is not possible to find it elsewhere.”

“We are all working with approximately the same material....humanity. It is how we feel about ourselves that makes the difference. It is what we tell ourselves that makes the difference.”

“Real strength comes not from pretending to be strong all the time, but from acknowledging our weaknesses and vulnerabilities when we feel that way.”

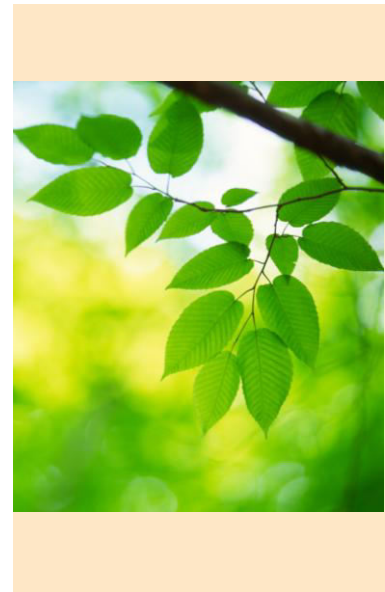
“For each of us there comes a time to let go. You will know when that time has come. When you have done all you can do, it is time to detach and surrender. Face your fears about losing control. Gain control of yourself and your responsibilities. Free others to be who they are; in so doing you will set yourself free.”

“There’s nothing about this that you can’t handle.”

“Life isn’t about waiting for the storm to pass. It’s about learning to dance in the rain.”

## Make a Commitment to Yourself

It is easy to allow yourself to become engulfed in your ill relative’s life and forget about your own needs, and yet maintaining an identity apart from your role as caregiver is ultimately the best “medicine” for you both. Treating yourself well every day and putting your own well-being first will ensure that your mental and physical health is protected and that you are better equipped to deal with the demands of the caregiver role.



Taking a break requires a commitment to yourself and may also require planning ahead. You may, for example, need to call on trusted friends and family to take a turn as caregiver for a short while. You may need to organize holidays and get someone to take your place while you are away. You may want to find out what services exist locally for short-term caregiving—for example, some hospitals have day centers where your ill relative can stay for the day and perhaps weekends.

As hard as it may seem, there are many ways to take a break during the day. The first step is becoming aware of what it is that you find fulfilling or, at the very least, a good distraction. For some, going to work is a great way to get their minds off of things at home. For others, being involved in a church organization or playing with their grandchildren may be the answer.

We encourage you to take the time to ask yourself, “What am I going to do for me?”, to take inventory of your interests and passions, and to build these things into your daily life. You may need time to reconnect with yourself, to remind yourself of who you are, what hobbies you used to enjoy, and the goals you once had for yourself. A journal can be useful to record your interests, hobbies, goals, and so on and to keep track of progress.

Some suggestions from our focus group on ways to look after yourself include:

**Make your physical health a priority.** The stress of care giving can take its toll on your body. Set aside time each day to exercise. Do whatever is possible—a 5-minute brisk walk with the dog, a 30-minute jog, 10 minutes of stretches, a round of golf, an exercise class at the gym, and so on. Make time to see your doctor if you need help with anxiety, stress management, sleep disruption, and any other issues you may have.

**Look after your emotional and spiritual health.** You may consider going to your church/temple/mosque, or reading inspirational books. Some people find yoga or meditation helpful in developing mindfulness and being “in the moment”. Gardening or getting back to nature somehow can be therapeutic for others. Positive affirmations can help focus on what’s right rather than what’s wrong.

**Keep in contact with friends who can support as well as distract you.** Resume your social life—for example, invite a friend to attend a hockey game, movie, lecture, and so on; or stay at home and invite a friend over to have coffee, watch the football game, or make a nice dinner together.

**Attend weekly family support groups.** Share your experience in a safe environment with others who truly understand what you are going through. Let yourself see that you are not alone in your struggles.

**Maintain work if possible or take up a volunteer activity**—for example, help at your kids’ school or preferred charity—to prevent engulfment in the illness and to provide valuable perspective.

**Allow yourself occasional “retail therapy”** and spoil yourself with something that makes you feel happy—new clothes, new golf club, a hair cut, manicure, pedicure, or flowers.

**Take a break and allow yourself to stop and do nothing.** Consider the option, “Don’t just do something, sit there”. Treat yourself to a mid-morning “time out” with a good cup of coffee, sit in the garden, or listen to relaxing music.

**Steal a few moments for yourself in the midst of your busy day**—for example, take a few extra minutes to drive the scenic route home from work, enjoy a light conversation with your co-worker, slow your pace and look around you, or stop to pat the dog.

Above all, **remain hopeful and expect success.**

## Thinking Traps

Sometimes one of the hardest parts of dealing with mental illness is trying to control the negative thoughts we experience in the course of our day. We can get trapped in a negative circle of unhelpful thoughts.

Cognitive behavioural therapy techniques (CBT) are used to help people change negative ways of thinking. These techniques can be self-taught and may be useful for helping you gain control over thoughts that aren’t helpful to you as a person or as a caregiver. By controlling your thoughts you can help to regulate your feelings and moderate your actions.

“By changing your thought, you will change your feeling. By changing your feeling you will most likely change your action or behaviour. You mainly feel the way you think.”

*Ellis, 1999*

Thoughts can be powerful evokers of feelings and actions, as illustrated in the following examples:

The Power of a Negative Thought: An Example:

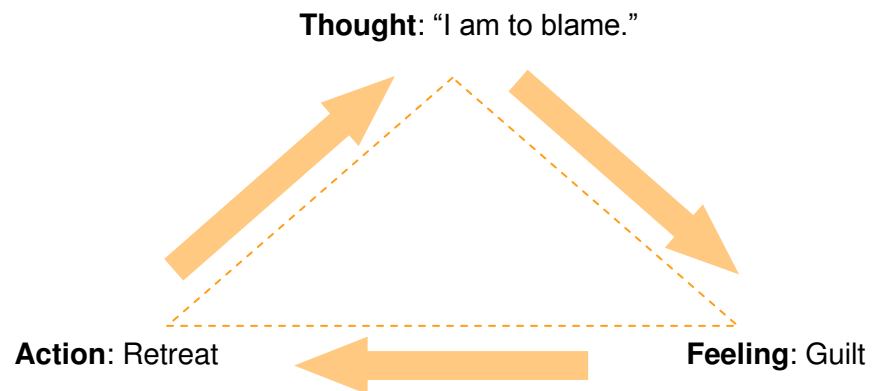
A. **Thought:** " I am to blame for this mental illness."



B. **Feeling:** Guilt, self-blame, shame.



C. **Action:** Retreat from people, maintain secrecy, try to cope alone.



When you find yourself having negative thoughts, look for evidence that can create a more balanced, more realistic point of view. Instead of, "It's my fault", a more realistic point of view would be, "Although I may not be the perfect spouse/parent/child, I did not cause my relative's mental illness".

The Power of a Positive Thought: An Example:

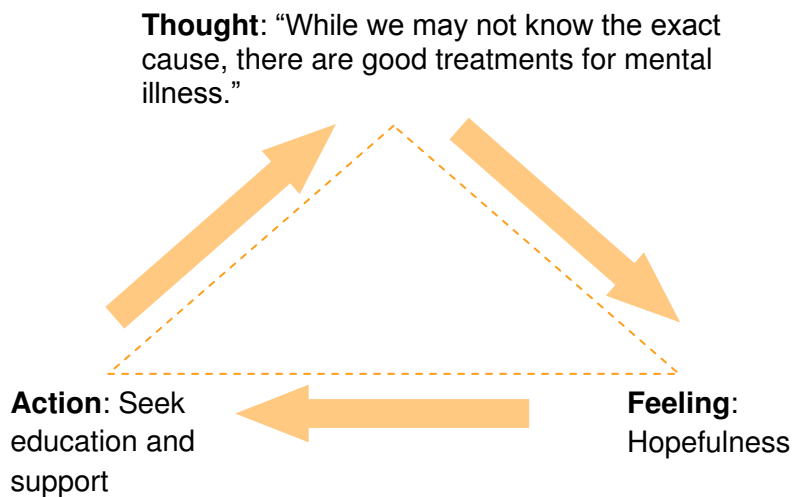
A. **Thought:** *"Although the causes of mental illness are still not completely understood by the professionals, there are good treatments available."*



B. **Feeling:** *Hopefulness.*



C. **Action:** *Seek education and support from professionals, family, and friends.*



## Distorted Thinking

Some negative thinking is referred to as “distorted thinking”. Habits of distorted thinking are as common as they are unhelpful. They are common amongst the population at large and not just amongst people struggling with a mental illness in the family.

### Types of Thinking Traps

There are many thinking traps, or “cognitive distortions”, that we all can easily fall into. Listed below are the 10 most common, as identified by David D. Burns, MD in his book, “Feeling Good: The New Mood Therapy” (1981):

1. *All-Or-Nothing Thinking*: You see things in black-or-white categories. If a situation is anything less than perfect, you see it as total failure.
2. *Overgeneralization*: You see a single event as a never ending pattern of defeat by using the words “always” or “never” when you think about it.
3. *Mental Filter*: You pick out a single negative detail and dwell on it exclusively. One word of criticism erases all the praise and good work you did.
4. *Discounting the Positive*: You reject positive experiences by insisting they “don’t count”. If you do a good job, you tell yourself that anyone could have done it as well.
5. *Jumping to Conclusions*: You interpret things negatively when there are no facts to support your conclusion. Two common reactions are mind-reading (you arbitrarily conclude that someone is reacting negatively to you) and fortune-telling (you assume and predict that things will turn out badly).
6. *Magnification*: You exaggerate the importance of your problems and shortcomings, or you minimize your desirable qualities. This is also called the “binocular trick”.
7. *Emotional Reasoning*: You assume that your negative emotions reflect the way things really are: “I feel guilty. I must be a rotten person”.
8. *Should Statements*: You tell yourself that things should be the way you had hoped or expected them to be. Many people try to motivate themselves with should and shouldn'ts, as if they have to be punished before they can be expected to do anything.
9. *Labeling*: This is an extreme form of all-or-nothing thinking: instead of saying, “I made a mistake”, you attach a negative label to yourself and think, “I’m a loser”.
10. *Personalization and Blame*: You hold yourself personally responsible for events that aren't entirely within your control.



The following gives examples of unhelpful, negative “cognitive traps” and their more helpful, realistic alternatives:

### **Cognitive Trap**

When stressful things happen, it is common for negative thinking to follow. As family caregivers, some of the following thoughts may be familiar:

I am alone with this.

I must sacrifice myself for him/her.

His/her recovery is more important than my wellbeing.

It is my fault.

It is up to me to fix this.

I must keep this secret.

I should not be having such a hard time coping with this.

He/she will never improve.

I must keep our lives under control.

I must keep control over him/her.

I can't stand this. This is awful.

This is unfair.

I must not expect anything of him/her.

### **Helpful Alternative**

Now is the time to look at how you may be distorting your thoughts and may be increasing your discouragement and anxiety unnecessarily. Next time you notice a negative habit of thought, repeat a more realistic phrase to yourself to contradict it, as shown in the following examples:

I need not do this alone.

I will do what I can without making myself a martyr.

My wellbeing is important as well.

This is not my fault.

This not my responsibility to fix.

There is no shame in this.

Why do I think this should be easy?

He/she will gradually improve. There is a light at the end of this tunnel although I can't see it yet

I can let go of having to control our lives through this.

I can let go of having to control him/her through this.

I may not like this, but I'll get through.

Life isn't fair. Why should I expect it to be? There can be growth for me in this.

It is important for me to develop appropriate expectations of him/her, as recovery gradually occurs, and to communicate these clearly.

## **How to Avoid Thinking Traps and Distorted Thinking: Focus on What's Right**

It is easy to get caught up with the bad events and gloomy situations we sometimes experience in our lives. The purpose of this activity is to encourage you to take a break from your worries and think about a piece of “good news”, about something that is going right in your life. Even when things look their bleakest, there are other things that happen in our lives that can be a welcome relief, even if just for a moment.

We invite you to take some time to identify something that is going well in your life. This could be something you enjoy doing, a relationship you have with someone, something you've done that you feel proud of, or something that just went well. It can be very energizing to remember these “bright spots” and realize that you helped in some way to create these good things.

Consider the following exercise:

- Think about your day. What happened that was positive?
- What aspect of this event pleased you the most?
- Why did this good thing happen? How did you help to bring it about?
- What qualities do you have that helped make this happen?
- What do these strengths say about you as a person?

A “gratitude journal” can be a useful place to record these thoughts.

## **Practice Problem Solving/Goal Setting**

Consider the following exercise:

- Write down a problem you are currently dealing with.
- What is the underlying goal attached to this problem? What would you like to see that is different from your current position?
- Suppose you reach your goal, what will be different? What will you be doing differently? How will you feel? Who else will notice? What will they notice about you that will tell them that you have achieved your goal?
- What steps have you already taken towards your goal?
- What strengths, skills, and resources do you have that will help to ensure you achieve your goal? What will be the first change that will tell you that you are moving towards your goal?

## Setting Future Goals

“Above all, try something.”

*Franklin Roosevelt*

When we have many things that take up our daily lives, it can be easy to live day-to-day without much thought towards the future. In this activity, we encourage you to think about goals for yourself. These goals can be small or large, but they must be clear, achievable goals.

Although small goals may at first seem insignificant, they can help to keep you focused on what is important to you as a person. Think about plans you may have had to put on hold or plans for the future. What is realistic now? What may be possible later on as your family member becomes more self-sufficient?

When setting goals, try to set time posts and think about what things would you most like to be different in one month, six months, one year, or five years?

Ask yourself the following questions:

- What is one step you can take now towards meeting a goal you’ve set?
- How will you know that you’re on track? What small changes will be evident?
- How will you know that you’ve met your goals?
- What will be different?
- Who will notice?
- How will you be feeling?

## Self-Care Chart

In this activity, we encourage you to think about the activities you do as part of your day-to-day life that help fuel your mental and physical health.

In the chart below, we have listed some general categories of activities that make up our daily lives. There is also space at the end to add your own individual activities. The goal is to think about how you can continue to maintain some or all of these activities in between caregiving.

Activity	How Often	Alone/With Company	Ways to Maintain
Favorite Exercise			
Fun Activities			
Hobbies			
Social Activities			
Favourite TV Shows			
Favourite Music			
Ways to Relax			
Other			

### Summary

Turning the focus of care toward you, the caregiver, is vital. It is as important as the care of your ill relative. Maintaining your own mental and physical health will ensure that you are well equipped to provide the ongoing care and support required during your ill relative's journey towards recovery—without losing yourself along the way.