



Guide for Informal Caregivers

ACKNOWLEDGMENTS

We wish to extend our deepest gratitude to all those who have helped in the realization of this bilingual guide. First, we would like to thank Mrs. Amélie Granger-Pouliot, a Ph.D. student at Laval University whose contribution, as part of an internship program, was instrumental in the production of this guide. A special thanks as well goes to Mrs. Audrey Potvin, a dedicated volunteer who's in charge of Scleroderma Quebec's support network.

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Finally, we would like to express our thanks to all scleroderma patients and their informal caregivers who completed the questionnaire, which was developed in the preparation of this guide.

The production of this guide was made possible through the financial support of the Foundation of Greater Montreal (FGM).

Scleroderma Quebec would like to express its sincere thanks to the FGM for the grant awarded to the organization as part of its community support program (Health and Wellness).



Foundation of Greater Montreal

A Scleroderma Quebec Publication
March 2016

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*In this document, the masculine generic refers to both the masculine and feminine genders and is used for conciseness purposes only.

EMOTIONS

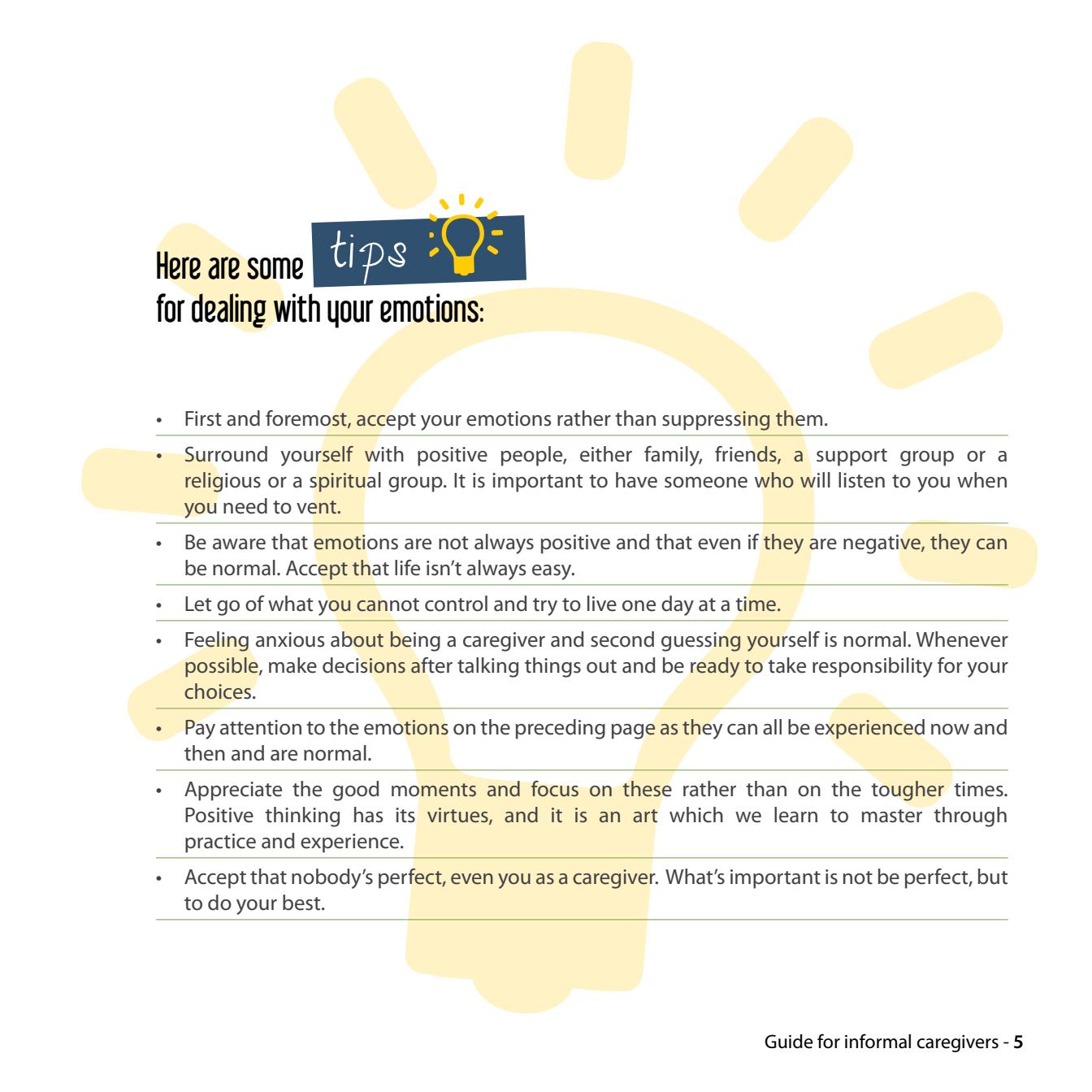


Here are some of the feelings that caregivers experience:

Denial - Anxiety - Fear - Anger - Resentment -

Guilt - Sadness - Acceptance - Joy -

Depression - Disappointment



Here are some *tips*  for dealing with your emotions:

- First and foremost, accept your emotions rather than suppressing them.
- Surround yourself with positive people, either family, friends, a support group or a religious or a spiritual group. It is important to have someone who will listen to you when you need to vent.
- Be aware that emotions are not always positive and that even if they are negative, they can be normal. Accept that life isn't always easy.
- Let go of what you cannot control and try to live one day at a time.
- Feeling anxious about being a caregiver and second guessing yourself is normal. Whenever possible, make decisions after talking things out and be ready to take responsibility for your choices.
- Pay attention to the emotions on the preceding page as they can all be experienced now and then and are normal.
- Appreciate the good moments and focus on these rather than on the tougher times. Positive thinking has its virtues, and it is an art which we learn to master through practice and experience.
- Accept that nobody's perfect, even you as a caregiver. What's important is not be perfect, but to do your best.

EMOTIONS

BURNOUT

What leads to a burnout?

As a caregiver, significant stress may develop over time because caring for someone is not learned overnight and requires a lot of energy. There is not enough time in one day to perform all the duties incumbent upon you inasmuch as caregivers are often required to take on several roles. Some caregivers will gradually put their own needs and responsibilities on the back burner. When caregivers neglect their needs, it becomes increasingly difficult for them to maintain a balanced physical and psychological health. As each day goes by, it gets harder and harder to keep up with various tasks and finding time for oneself is more and more difficult. That's when exhaustion sets in.

So make sure you are caring for your own needs as well as those of your loved ones. If you are not healthy in mind, body and spirit, you cannot be an effective caregiver.

A burnout often occurs when life feels out of balance, when one tries to live up to other's high expectations or one's own at the expense of self-care. Some caregivers want so badly to live up to their responsibilities that they feel they have to turn into some kind of superhero that can do it all, setting unrealistic expectations for themselves that they can somehow meet all the needs of others, while neglecting their own needs and desires. This approach sets them up for failure. It drains their energy, saps their strength, weakens their defence mechanisms and leaves them resourceless. The effects of stress build up over time and become so overwhelming that caregivers find themselves in need of support. Caregivers must avoid falling into this trap at all costs.



Statistics: Portrait of caregivers

While about 20% of the general population report a high level of psychological distress, this figure ranges between 30% to 50% for caregivers!

Studies have shown that psychological distress is as much as 25% higher among caregivers than in the general population.

About 20% to 30% of caregivers who have physical health problems are depressed.

What are the signs and symptoms of a burnout?

- Feeling tired most of the time (including emotional, physical and mental fatigue)
- Decreased sense of satisfaction
- Negative attitudes
- Low self-esteem
- Feeling easily irritable or annoyed
- Feeling frequently low and exhausted
- Difficulty sleeping even when tired and not feeling rested after a full night's sleep
- Lack of energy
- Constant worry or concern
- Feeling overwhelmed and never accomplishing all that was planned
- Forgetfulness and missing important appointments

EMOTIONS

DAILY STRATEGIES TO PREVENT
OR MITIGATE EXHAUSTION



First and foremost, you must learn to accept that your own needs are as important as those of others. Next, you must try as much as possible to apply the following tips:

- Take into account your own personal limits and set appropriate boundaries for yourself and others.
- Learn to recognize guilt and don't let it overwhelm you.
- Choose an activity you love and practice it daily or weekly.
- Join a support group or use support services in your local area (see p.18 of this Guide).
- Surround yourself with people who will listen when you need to vent and talk openly about your emotions.
- Make an appointment with the doctor or other health specialist when a physical health problem arises.
- Don't forget to set some time aside each day to relax.
- Make sure you are eating healthy and well balanced meals.
- Maintain healthy living habits such as getting regular exercise and enough sleep in order to keep your energy. Yoga, meditation and breathing exercises are great ways to relieve stress, restore energy, improve concentration and mood, and get a better handling of your emotions.
- Allow yourself time to relax EVERY day, to do something you enjoy that allows you to free your mind, to focus on other things or simply relax.
- Before agreeing to do something, make sure that you have both the time and capacity to follow through.

**Most importantly, you must balance your needs with those of others.
It is a constant challenge, one that is very difficult to achieve.
However, keep in mind that as a caregiver, taking the necessary steps to prevent burnout
will allow you to better support yourself and the person you care for.**

EMOTIONS

ASSERTIVENESS

Assertiveness is an essential quality to live in harmony with others. It allows us to respectfully express our opinions, feelings and needs. For caregivers, it is even more important to be assertive.

Here are some benefits of being assertive:

- Showing your true colors, being genuine with yourself and others.
- Feeling better about yourself.
- Being more confident.
- Feeling much less frustrated, hurt, angry or submissive.
- Being better understood.
- Having more honest and open personal relationships.

Some

tips



on how to be more assertive:

- **Speak in the first person (“I”):**
 - Voice your feelings.
 - Explain what circumstances caused you to feel this way.
 - Propose a solution that involves the other person.
- **Learn to say NO and dare to say YES when desired:**
 - Recognize your limits and don’t exceed them.
 - Learn to respect your own needs and wishes as much as you respect those of others. If you never say no because you want to please others, you are neglecting your own needs and wishes.
 - Set aside time to do things for yourself and have relaxing, positive moments without feeling guilty.
- Stand up for what you believe in, put forward your ideas and opinions confidently.
- When faced with a request, take time to think it through before accepting.
- Listen to yourself, learn to trust your feelings, consider your own limits and priorities before accepting to do anything.
- Don’t be afraid to assert yourself. Establish and maintain an open mind when listening to others’ ideas and feelings.
- Express yourself calmly and respectfully to facilitate exchange of views and promote dialogue.

Finally, don't forget that everyone has the right
to express their feelings and opinions!

TAKING BREAKS

Caregivers must not forget to take time for themselves, even if this can bring about feelings that are hard to deal with, like guilt and fear. These moments of respite are essential to replenish your energy, which in the long run, will allow you to take better care of your loved one. Hence, this respite will be beneficial for the care receiver and the caregiver alike.

First, you must plan your time carefully by making a schedule and a list of things to do that will allow you to be better organized. In this schedule, you must not only provide for free moments to cope with unforeseen circumstances, but more importantly, set aside time for yourself to unwind.

Tips to take breaks and replenish your energy

- Take a break from your hectic daily schedule and set aside some time for yourself every day.
- If you cannot leave the person you are caring for alone, ask someone you trust, whether a friend, family member or someone else, to help out at home during your breaks outside the house.
- Don't allow guilt or fear to set you back, but rather see the respite as helping you to move forward by regaining your strength and vitality, thus becoming a better caregiver.
- Accept that you too, as caregiver, may need support and time to rest (see next page).

THE IMPORTANCE OF DELEGATING

As a caregiver, it is easy to get carried away by gradually accumulating the duties and tasks at hand. It is not uncommon for caregivers to want to take on everything: household chores, financial responsibilities, meal preparation, medical appointments, groceries, etc. Some even do all this while remaining active in the labour market. When one plays all these roles, exhaustion can quietly set in. That is why care must be taken not to go too far along this route, recognizing at an early stage when the work load or stress is too much and that we are no longer able to do everything.

Tips for sharing responsibilities

- Ask a family member or friend to help with the groceries. Check for available resources to optimize home menus and help with meal preparation. Preparing meals at home in advance can be a valuable option to consider. Also, you might ask someone you know to prepare meals for you once a week. Finally, a meal service is sometimes offered by the CLSC (i.e. local community service centre). Call your local CLSC to find out if they offer this service.
- Consider the possibility of hiring someone to do the house and/or yard maintenance (outdoor work such as mowing the lawn). Students sometimes offer these services at lower cost.
- If you are on good terms with your neighbors, make an arrangement to have them take out your trash and recyclables weekly.
- When possible, alternate who takes your loved one to their medical appointments, freeing up your time.
- Accept help offered by family, friends and neighbors. You should not feel uncomfortable or embarrassed when accepting support. This help is valuable and will allow you to be a better caregiver for your loved one (see section below, p. 14-16).

TAKING BREAKS

ACCEPTING HELP



Statistics:

According to Statistics Canada, the role of caregiver has far-reaching consequences.

Here are some statistics:

About half of those who care for a spouse or a child have reported at least 5 symptoms of psychological distress and a third of them have had to see a health-care professional for a medical condition resulting from their caregiving responsibilities.

Portrait of caregivers 2012, Statistics Canada.
(www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.pdf).

Despite these disturbing figures showing just how challenging and demanding caregiving can be, most caregivers are still reluctant to ask for support. There are a number of reasons behind this reluctance from the caregivers, some of which might also explain their willingness to bear alone all the responsibilities that their work entails; but one must clearly understand that not accepting or asking for support is a very risky business, which most commonly leads to burnout.

Acknowledging the need for support:

More than anything, the first step that needs to be taken is to recognize that nobody is a superhero, and that based on the previous statistics, if a caregiver does not seek help, he or she is at risk of burning out. Letting go and understanding that you can't overdo it is important. Taking time for yourself, accepting help from others and replenishing your energy is actually a long-term investment which will allow you to breathe better and support the person you are caring for.

How to ask for help

First and foremost, you must clearly identify your needs and write them down. Only after this first step is taken can you focus on solutions. You must also learn to share your needs with family members and close friends and specify what kind of support you require.

Once needs have been identified, you need to take stock of all available resources that can help. These resources may include family members, friends, neighbors, but also external agencies and support programs. Asking small services of several people can relieve you from some of your duties and responsibilities without any fear of being annoying or too demanding for others.

Finally, once these steps had been completed, reach out to those people and/or organizations that may offer support (see pages 16-18).



on how to make a successful appeal for help:

- Draw up a list of the needs for which you would like support.
- Draw up a list of family members and friends who might be able to support you.
- Think of the proverb “Nothing ventured, nothing gained”.
- Maintain a positive and proactive attitude turned toward action and results.
- If you apply for support from organizations, be aware that the wait can be long and the steps may seem complicated. Take things one step at a time, do not lose hope and ask someone to help you through this process (e.g. social worker).
- Find out about the resources that are available to you (see pages 18-19).
- Remember that asking for support and not doing it all on your own will allow you to have more quality time for yourself. Try to give yourself at least a half hour a day to unwind.

HOW TO HELP?

- Listen when the care receiver or caregiver expresses their needs.
- Ask each party to make a list of their needs.
- Go through the list together to discuss these needs and make sure that everyone understands them.
- Find solutions together or with other family members or close friends to make sure that everyone's needs are met.
- Maintain honest and open communication. Words that are not spoken cannot be heard and even less understood by others.
- Implement the solutions that were found, and test them to see if they work.



If the solutions put forward are addressing everyone's needs efficiently, continue applying them. Otherwise, you will need to adjust and try out other solutions that can meet the needs of both the scleroderma patient and the caregiver.

HOW TO HELP A PERSON LIVING WITH SCLERODERMA?

- Driving and/or accompanying the care receiver to medical appointments.
- Help with getting dressed (e.g. fastening small buttons).
- Housekeeping (e.g. washing dishes, vacuuming, household maintenance/ home support).
- Outside maintenance (e.g. mowing the lawn, shoveling snow, landscaping).
- Running errands.
- Doing the laundry.
- Help with personal care.
- Help with tasks that require dexterity (e.g. opening jars).
- Shovelling the driveway and starting the car in winter to help the person with scleroderma avoid the cold.
- Cooking.
- Asking questions to find out what can be helpful to the person living with scleroderma.

OTHER NEEDS IDENTIFIED BY PEOPLE LIVING WITH SCLERODERMA

- Moral support during tough times and flares.
- Emotional support (e.g. compassion, love, listening).
- Inquiries about financial assistance, if needed.
- Foot care.
- Change of bandages and administering injections, if needed.
- Assistance in walking up and down stairs.
- Arrangements for adapted transportation services.
- Short massages (often very beneficial to scleroderma patients).

RESOURCES FOR PEOPLE WITH SCLERODERMA AND CAREGIVERS

To learn more about the disease:

- Scleroderma Association of B.C. website: sclerodermabc.ca (provides a wealth of useful information about scleroderma)
- Support groups provided via Scleroderma Association of B.C. (“Support and Self-help Groups” tab at sclerodermabc.ca)
- Articles on Scleroderma (can be accessed via the “Articles and Publications” tab at sclerodermabc.ca)
- Activities related to scleroderma (“Upcoming Events and activities” tab at sclerodermabc.ca)

Family and friends:

- Family (son/daughter, father/mother, grandparents, grandsons/granddaughters, cousins, aunts/uncles, etc.)
- Friends (draw up a list of friends who can actually be there for you)
- Neighbors (often underestimated, neighbors can be an important resource)
- Coworkers
- Church or religious group members
- Members of support groups

Medical Resources:

- Attending physicians (family doctors or medical specialists, etc.)
- Podiatrist
- Occupational Therapist
- Physiotherapist
- Pivot nurse/home-care nurse (Note: Scleroderma Quebec has a nurse on staff who can be of service, if needed.)
- Pharmacist (easily accessible and helpful)

Wellbeing Resources:

- Psychologist
- Massage Therapist
- Osteopath
- Acupuncturist
- Fitness Trainer
- Nutritionist
- Yoga

* A first-line resource, the CLSC offers all kinds of services, from listening to home services. Do not hesitate to visit your neighbourhood CLSC to find out about available services.

External Resources:

- The Caregiver Network (TCN): <http://thecaregivernetwork.ca/>
- Caregiver Connect: www.caregiver-connect.ca/en-us/pages/home.aspx
- Mammoth Magazine article on Caregivers:
http://www.humanstress.ca/documents/pdf/Mammoth%20Magazine/Mammoth_vol10_EN.pdf



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