

# Caring for Aging Loved Ones

TIPS AND TRICKS FOR FAMILY CAREGIVERS

Québec



### **AUTHOR:**

Francine Ducharme, Ph. D.,

Research Centre, IUGM

Desjardins Research Chair in Nursing Care for Seniors and their Families

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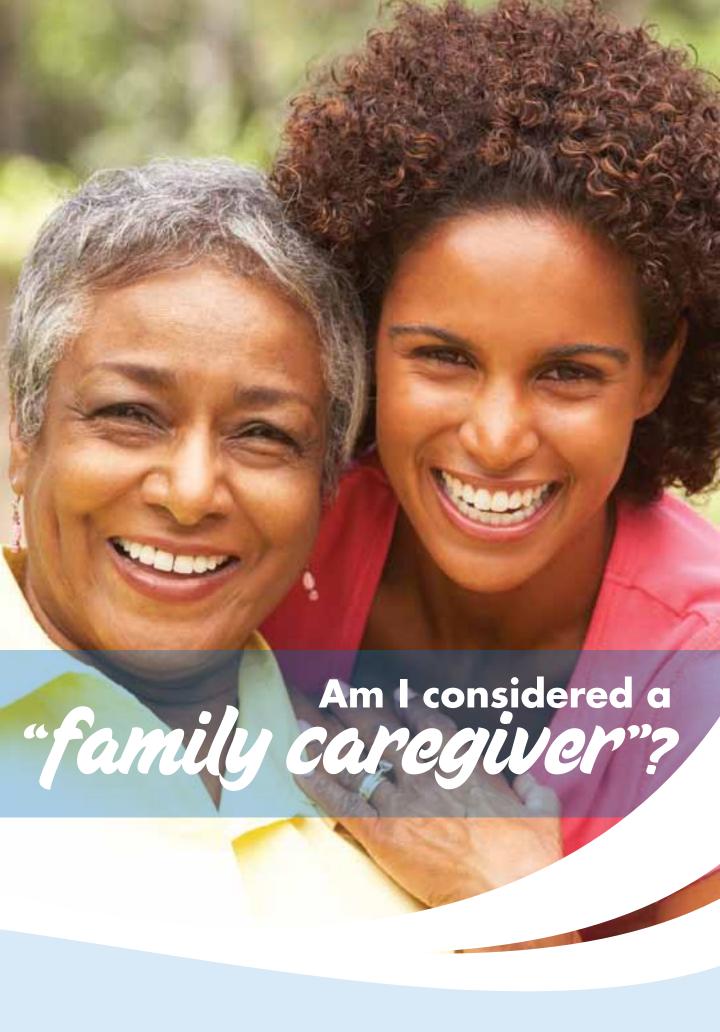


## Summary

An	n I considered a "family caregiver"?
Kn	owing how to ask for support
8	Create a family council, when necessary
Ac	cepting emotional support
11	Have someone to confide in
11	Avoid isolation
Fin	ding material support
Re	ceiving financial support
13	Tax credits
13	Financial Assistance Program for Domestic Help Services
Ha	ving a mandate in anticipation of incapacity
Loc	oking after yourself
17	Use strategies
18	Do away with guilt
19	Recognize the signs of exhaustion and depression
19	Reduce your stress
Pla	cing a loved one in a long-term care residence
23	Ask yourself the right questions
23	Speak to stakeholders
24	Find the right facility
25	Find out about costs
25	Initiate the placement process
26	,
27	Don't hesitate to reach out and ask for helpagain

Choosing a palliative care centre

To sum up





- Lending support to a parent with reduced autonomy?
- Living with a parent who can no longer live on their own due to the scope of care and assistance required?
- Living with a spouse afflicted by a disease that requires assistance?
- Overseeing the well-being of a parent or spouse living in a residence for long-term care?
- Devoting time to care for or lend support to a family member or friend with health problems or loss of autonomy?

If you answered "yes" to any of these questions, you are by definition, what is known in Quebec as a "family caregiver".

Being a "family caregiver" simply means overseeing the well-being and quality of life of a person who needs our support.

This brochure consists of several tips and pointers intended to help make your life easier, and to help you look after yourself as well.

Enjoy the read!



Many caregivers find it difficult to reach out and ask family members, friends, community agencies, health services and private companies for support, regardless of whether the help is for their loved one or themselves.

Have you ever heard yourself make any of the following statements?

- My friends and family should know that I need help;
   I shouldn't have to ask them.
- I'm used to doing it on my own, I don't need help.
- Everyone is already so busy with their own families and jobs, I don't want to impose.
- I'm still capable of doing it on my own.
- I'm weary of how my loved one will react if I entrust their care to someone other than me.
- In reality, it's not all that demanding. I'm sure that others who are in similar situations do much more than me and don't need help.
- Asking for help is so complicated.

or...

Maybe at some point down the road.

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Don't wait to be at wit's end before asking for help!

## Create a family council, when necessary

For some, creating a family council may be the key to receiving much needed emotional, material and, in some cases, financial support. In fact, securing clear commitments rather than promises from your extended family could mean:

- A more equal division of health care tasks
- Respite and time for outings
- Help finding care and services
- A more equitable division of expenses

To establish and maintain open lines of communication with your family members and to benefit from their support, you must first begin by accepting your own limits and allow others to take their rightful place, while taking their skills and preferences into consideration.

Is **distance** preventing certain family members from helping you care for your loved one?

## Tip

If certain family members cannot be physically present, there is no reason why they cannot help you with certain tasks such as looking up information, making phone calls, filling out forms, etc. Send them the links to the websites and the phone numbers in this brochure and assign them the task of finding information for you! Are their **agendas overflowing**? No one seems to have any time to help you out?

## Tip

Take a close look at everyone's schedule and find a suitable time that can work for everyone. Try establishing a fixed schedule rather than one that is variable.

Example: Your brother takes your mother out for dinner on Thursday nights. If you do not know at what time he will drop her off, you will spend your entire evening at home, waiting.

However, if you and your brother agree on a set pick-up and drop-off time, you can go out and enjoy yourself.

Is your loved one no longer able to make sound decisions? Do some family members disagree with the choices you are making on behalf of your parent?

## Tip

Important decisions can cause serious conflicts within a family. To prevent this from happening, bring up important issues during family council meetings. This way, everyone can have their say and voice their opinion, and reaching a consensus will be easier.



# Accepting emotional support

## Have someone to confide in

The importance of having someone you can confide in cannot be overlooked. Whether it is a trusted individual or a group, having someone with whom you can laugh and cry and who is there to listen and make you feel better, is crucial. A confidant can be a family member, a friend or even a nurse who cares for your loved one and with whom you feel comfortable.

## Avoid isolation by having a strong social support system

Take time to socialize. Socializing and recreational activities are essential and prevent isolation. For example, joining a support group for caregivers will provide you with a social outlet where you can get information and support, as well as listen and share with others who are in similar situations. Going out with friends is another way you can look after yourself and receive much needed support. Having a social support system will have a positive impact on your morale and your health.



# Finding material support

There is no shortage of needs when caring for a loved one! It is important to know that there are countless types of services available to help simplify your life: housekeeping, home delivery, meal preparation, respite care services, volunteer transportation services, etc. This sort of material support however, is often difficult to find.

## **Tips**

- Call on family members and divide tasks.
- Call on your local CLSC for support or ask them to steer you
  in the right direction so you can find solutions to your needs.
- Consult the list of agencies that can offer support in your area or visit the following site: www.aidant.ca/organisme.
- In the event of a **non-emergency**, call Info-Santé by dialling 811. This number can be dialled from anywhere within the province of Quebec (except Northern Quebec) at any time, day or night. Dial 811 to speak to a health care professional who will be able to answer general health-related questions **or** direct you to the appropriate service within the health and social services network.

# Receiving financial support

The services offered by the CLSC may be insufficient and, as a result, you may need to hire a nurse or housekeeper, for example. You may also have to retain the services of private sector suppliers. Do you know that you can take advantage of tax credits and financial assistance for the costs incurred by these services?

For more information on the

## Financial Assistance Program for Domestic Help Services:

Visit the following site: www.ramq.gouv.qc.ca

or

Call one of the following numbers:

If calling from the Quebec City area: 418 646-4636

If calling from the Montreal area: 514 864-3411

If calling from elsewhere in Quebec,

toll free: 1 800 561-9749

For more information on tax credits:

Consult the

Tax credit for

home-support

services for seniors

at:

www.revenu.gouv.qc.ca

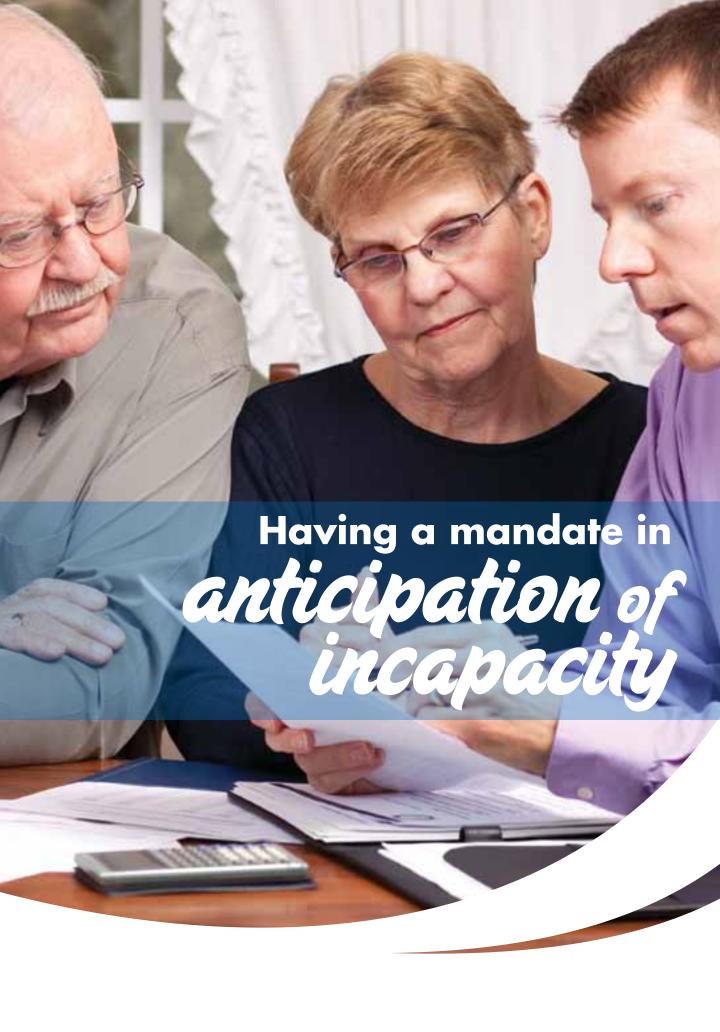
or

Call one of the following numbers:

If calling from the Quebec City area: 418 659-6299

If calling from the Montreal area: **514 864-6299** 

If calling from elsewhere in Quebec: **1 800 267-6299** (toll free)



Over time, the weakening of your loved one's mental capacities, due to advanced age or illness, may result in an inability to express their wishes and see to their own health and safety. This is why it is strongly advised that your loved one draft certain legal documents - such as a mandate in anticipation of incapacity - while they are still of sound mind.

The mandate in anticipation of incapacity is defined by the Curateur public du Québec, as "a written document by which a person (mandator), appoints, while he is still lucid, another person (mandatary), to look after his person and/or the administration of his property, in the event that illness temporarily or permanently deprives him of his faculties".

The mandatary is therefore called on, among other things, to consent to medical treatment delivered to the mandator. Deciding on the direction of a loved one's care can be trying and difficult. This is why talking to your loved one about their wishes prior to their incapacity is highly recommended. This way, if and when something does happen, you are better equipped to convey your loved one's instructions and wishes to the health care teams.

For more information, dial 1 800 363-9020

or

visit the website of the Public curator

www.curateur.gouv.qc.ca



## **Use strategies**

It is all too easy to forget about yourself when caring for a loved one! Because caregivers are so focussed on the health of the person they are caring for, they often overlook the importance of taking care of themselves. In fact, caregivers have a higher risk of physical and psychological exhaustion. Take care of yourself before you reach that point.

You are unique! Opt for strategies that best suit your needs, capabilities and skills.

## **Tips**

- Indulge yourself. Don't feel guilty.
- Spoil yourself, do something for yourself, look after yourself for a change.
- Learn how to accept help.
- Remember that you cannot do it all on your own: your resources and capabilities are limited. Once in a while, remind those close to you.
- Find a haven of tranquility, a place all your own where you can spend at least 30 minutes a day, where you can rest, relax, recuperate, listen to music you enjoy, etc.
- Accept the unavoidable failures and rejoice in your successes
   as small as they may be.
- Learn how to impose boundaries and to say no.
- Reenergize through laughter and play.

## Do away with guilt

Those who care for loved ones, day in and day out, experience a wide range of emotions. Even though some emotions are healthy and completely normal, others are detrimental, especially if they are disproportionate to the situation that caused them. The most common unpleasant emotions reported by caregivers are anxiety, hostility, sadness, fear and guilt.

Almost all family caregivers experience guilt at some point or another. Do you belong to that majority?

### Have you ever felt:

- That you don't measure up?
- That you're not doing things properly?
- Regret after having or not having done something?

## Don't feel guilty if:

- You are healthy and your loved one is ill
- You take time to have fun, laugh, relax
- You don't feel like shouldering all the responsibilities involved in ensuring the well-being of your loved one
- You wish your life would revert back to the way it used to be so you can have some sense of normalcy
- You have lost your composure in front of your loved one
- You have thought about placing your loved one in a residence for long-term care or have already done so

## Recognize the signs of exhaustion and depression

For most caregivers, stress is part of daily life. It can however, have serious repercussions on one's health. Intense stress or stress accumulated over a long period of time can predispose you to exhaustion and even depression.

Signs that stress may be having a detrimental effect on your health include:

- irritability
- anxiety
- being overly emotional
- significant increase or loss of appetite
- loss of interest in your favourite activities
- sleep-related problems (not enough or too much sleep)
- frequent health problems

Do not hesitate to see your doctor if you have one or several of these signs.

## **Reduce your stress**

Despite all your good intentions, you will inevitably experience moments of stress in your role as caregiver. Activities such as meditation, yoga, and walking are great for managing stress as they allow you to take a step back and be better equipped to deal with situations as they arise.

## No one is perfect.

Accept your limits because you are doing your best.

As a caregiver, your most important asset is your physical and psychological health.

## Tip

Below is a 5-step approach that has been shown to be successful in helping manage stress.

## 1. Take a look at your situation

Take a look at the whole picture: what are the positive aspects of being a caregiver (those with which you are comfortable) and what are the negative aspects (those that irritate you).

## 2. Make changes

Take whatever aspect bothers you most to the point of wanting to make a change.

## 3. Goal(s)

Establish one or several goals that are both realistic and appropriate to help you deal with the issue you are having.

## 4. Strategy

Identify an effective strategy that has been tailored to help improve the situation and test it out.

If the situation can be changed, the problem-solving approach below may be of some help to you.

- A) Define the problem
- B) Look for solutions
- C) Determine the advantages and disadvantages of each of the solutions
- D) Choose the solution that is best for you
- E) Develop an action plan
- F) Implement the action plan
- G) Assess the results

If the problem is not resolved, try again with a different solution...

If the situation cannot be changed:

The best strategy may be to work on changing how you think about things. By reframing or by changing the way you see something, you may see the situation in a different light, and, as a result, you may find it easier to live with. Negative thoughts are often distorted and are usually not an accurate reflection of reality. Shifting the way you think about something will force you to examine your feelings and will prompt you to ask yourself some important questions. For example:

- Why is this situation having such an effect on me?
- How can I think about this situation in a more helpful manner?
- When I replace a negative thought with a more helpful thought, what kind of an effect does it have on me or the situation?

### 5. Assessment

Conduct an assessment of the strategy you used and determine whether you reached your personal goal.

Would you like to learn more about the approach developed by the Desjardins Research Chair in Nursing Care for Seniors and their Families team? Order the "A five-step approach to reducing your stress" brochure, free of charge, by writing to:

Library

Institut universitaire de gériatrie de Montréal 4545 Queen-Mary Road Montreal, Quebec H3W 1W4 514-340-2800, extension 3262



## Ask yourself the right questions

At some point in your journey as caregiver, you may find yourself thinking about placing your loved one in a residence, due to the complexity of the care and tasks you are required to perform on their behalf. Among the many decisions you are called upon to make in your role as caregiver, making the decision to place a loved one in a long-term care facility is, without a doubt, the most difficult. Before dismissing this option, ask yourself the following questions:

- Is delaying long-term care a good idea?
- Is it wise to wait for an event that would cause both parties to be distressed?
- Will I be ready, at some point, to make this decision?

Consider the current needs of your loved one but, more importantly, think about their future needs. Ask yourself the following questions:

- Am I equipped to meet all my loved one's needs?
- Am I still able to devote as much time and energy to my loved one without putting my own health at risk?
- Does the care required by my loved one involve skills
   I don't have?

## Speak to stakeholders

If you are starting to think about a long-term facility as a solution to ensuring your mutual well-being, speak to healthcare and social service workers. They will help you weigh the pros and cons of this option.

Learn to recognize your limits before it affects your health.

## Find the right facility

Although there are several types of residences to choose from, you want one that truly suits the needs of your loved one. Your loved one's level of autonomy, number of care hours required and income will be determining factors in this decision. It is recommended that you visit several facilities before making your choice. Remember that your local CLSC can provide you with information on which facilities in your area are right for your loved one. Here is what is available:

## • If your loved one is semi-autonomous

Type of resource	Consult
Private residences for seniors with services (meals, housekeeping, etc.)	On the web: Register of residences for the elderly or your CLSC
Intermediate resources: residences connected to a public establishment	Your CLSC
Family-type resources: facility that can accommodate up to 9 seniors who are referred by a public facility and require low level supervision	Your CLSC

## If your loved one has limited autonomy and requires several care hours each day and close supervision

Type of resource	Consult
Nursing homes or long-term care	The web for the list of
residential centres (CHSLD)	nursing homes in your
	area or your CLSC

### Find out about costs

Costs associated with residential facilities for semi-autonomous seniors vary based on the services offered. Be careful! In addition to the cost of the room, fees for services such as meals, transportation, recreational activities, laundry and even certain types of care are often added.

In nursing homes (CHSLD), fees are established by the provincial government based on the type of room, number of beds and personal income. It is important to know that if your loved one does not have the financial resources to pay, they can benefit from reductions.

## Initiate the placement process

To apply for admission to a residence for long-term care, refer, once again, to your local CLSC. They will be able to put you in touch with a doctor or social worker who will help you with the request.

They will then evaluate the needs of your loved one and initiate the request for long-term care by indicating the name of the centre in your area where your loved one could reside, based on their needs.

The request is then sent to the Agence de la santé et des services sociaux committee in your area who will review the file.

The preliminary steps can take anywhere between 4 and 6 months depending on the area. It can, on occasion, take even longer.

## Continue in your role as caregiver

Placing your loved one in a residence for long-term care does not mean that your role as a caregiver will end. The tasks that were once heavily focussed on care and supervision will decrease significantly and attention will shift to other responsibilities such as visiting your loved one, preparing their favourite meals, running errands, and overseeing their quality of life and well-being.

## Don't hesitate to reach out and ask for help...again

The guilt associated with placing your loved one in a residence may compel you to spend several hours a day visiting, putting your own health at risk yet again.

Furthermore, you will be dealing with new concerns such as:

- Ensuring the quality of care delivered to your loved one.
- Speaking to health care personnel on behalf of your loved one in the event of severe loss of autonomy, especially if you are dealing with memory loss.

You may notice that although your loved one is now living in a residence, your stress level is just as high as before. The source of your stress is now tied to your loved one's new living environment – a new reality you will have to adapt to and deal with.

That said, even after you have placed your loved one in a residence, emotional and material support from your friends and loved ones remains invaluable. The advice and tips given to help you get help and support, as well as the strategies aimed at helping you look after yourself, still apply...

# Choosing a palliative care centre

You may have decided to continue caring for your loved one at home, in spite of the severity of their illness. There may come a time however, when the care required by your loved one goes beyond what you can provide, and you may come to the realization that you need more help.

With regards to your loved one, do you feel:

- Overwhelmed when it comes to managing their pain?
- Unable to relieve symptoms of discomfort?
- Powerless to offer the support and comfort needed by both them and you?

It may be time to think about end-of-life or palliative care.

The attending doctor or CLSC will be able to steer you towards the options that could work for you.

In Quebec, most hospitals set aside a certain number of beds for palliative care. Twenty or so large hospital centres have also set up units specialized in end-of-life care. There are also palliative care centres in many areas that cater mainly to cancer patients.

Regardless of where your loved one goes, a team of specialized caregivers will do everything to make your loved one's remaining days as comfortable and dignified as possible.

## To sum up

The role of family caregiver is often fraught with consequences. You now know that there are many tools at your disposal that are aimed at helping lighten your load. Don't be afraid to use them and, remember above all else, that you must look after yourself!

