Caregivers to the Elderly

Maintaining Life Balance while Caregiving

Information and Support Guide for Caregivers

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L'APPUI POUR LES PROCHES AIDANTS D'AÎNÉS LAURENTIDES

Centre intégré de santé et de services sociaux des Laurentides
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* Note that the electronic version of this guide is available free on L'APPUI's website www.lappui.org.

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Accompagner tout en gardant l'équilibre

This guide is designed to provide information to people caring for the elderly and to those who will unexpectedly take on that role. It offers advice on various aspects of care as well as useful hints for adjusting your lifestyle and living arrangements to help ensure a better quality of life, both for the caregiver and for the elderly person being cared for. In this guide, we will be dealing with the following issues:

- **Finding your way as a caregiver**
- **Avoiding burnout**
- **Organizing daily life**
- **Planning for the future**
- **Being informed**
- **Supporting a loved one at the end of life**

Given that available programs and services are subject to frequent change, we remind the reader that the purpose of this document is to serve as a resource tool, and that the specific details of programs and services must be obtained directly from the source provided in this guide.

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How to use this guide

Question

This icon indicates a frequently asked question. Rest assured, you are not alone!

Conclusion / Answer

This arrow appears when we provide you with a conclusion or an answer to your questions.

Thumbs up

When you see this icon, read carefully: it contains very useful advice.

Important

This symbol accompanies very important elements. A priority must-read!

Quotation

To enliven the text, we have incorporated some quotations, identified by this symbol.

Useful link

Indicates a reference to other resources, to websites or to other sections.

Section 1

Support

Fact Sheet

Finding Your Way as a Caregiver

1

The caregiver is a person who invests time, without pay, to provide care and regular support at home to a senior with major or chronic disabilities, whether as a result of aging, accident or illness.

Do you help your father, your mother, your spouse to...

Look after their personal hygiene, maintain their dwelling, prepare their income tax returns or fill out other documents, go to the doctor or to other appointments, etc.?

Do you help a neighbour, a relative, a friend to...

Run errands, prepare meals, go out, go grocery shopping, clear the path of snow or cut the grass, undertake tasks, provide treatments, etc.?

If so, you are a caregiver.

Devoting your time to helping someone makes you a caregiver. It's that simple.

Who is a caregiver?

Most often, the caregiver is a member of the family, whether a spouse, a son, a daughter, an a nephew or a niece. But it can also be a friend or a neighbour! In short, the caregiver doesn't necessarily live with the person being cared for. However, no matter the nature of the care and services provided, the helping relationship always includes an important emotional component.

How does one become a caregiver?

Sometimes, as the result of an accident or an illness suffered by someone close, you suddenly become a caregiver. But, more often than not, it happens below your radar: the health of someone you love declines, that person loses independence and, over the course of weeks and months, you take on more responsibilities.

Does a caregiver really need help?

Undertaking the care of a loved one is not necessarily the result of planning or of an informed choice. In reality, most often it is the pressure of events that results in our heading down that path, arm in arm with the other person, without knowing in advance what awaits us. We can't be ready for everything and getting a bit of help can make a big difference.

A Caregiver's Bill of Rights

I have the right:

- To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.
- To seek help from others even though my loved ones may object. I recognize the limits of my own endurance and strength.
- To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.
- To get angry, be depressed, and express other difficult feelings occasionally.
- To reject any attempts by my loved one (either conscious or unconscious) to manipulate me through guilt, and/or depression.
- To receive consideration, affection, forgiveness, and acceptance for what I do, from my loved ones, for as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.

Source: Jo Horne, Today's Caregiver, Miami, Florida, www.caregiver.com

Fact Sheet 2

Learning to Ask for Help

With love and devotion, caregivers do their best to fulfill the needs of their loved ones. You need to remember that, to continue helping a loved one, you must be in shape to do so and know how to help yourself. For example, you need to:

- **Use existing care services** (information, psychosocial support, respite, etc.).
- **Learn to set limits, to assert yourself.**
- **Allow yourself periods of respite.**

"Be good with others and with ourselves. Help them to live, help ourselves to live; that is real charity."

— Émile-Auguste Chartier

What to do?

- Get informed about the specifics of the illness suffered by your loved one and the best approach for their care.
- Recognize the signs of exhaustion as well as your own needs.
- Recognize the signs of negligence, and, to avoid it, accept that others can take over from you.
- Appeal to your network (family, community) without feeling guilty.
- Consider other options once the limits of homecare are reached.

Sensitize the person being helped

To avoid exhausting yourself, you will sometimes have to change the way you provide care to your loved one. They must learn to accept that someone other than you will provide care. You will find helpful resources in the section Useful Links (Section 6, Fact Sheet 43).

Raise the awareness of your family and loved ones

To gain the moral and physical support of your family, write down everything that you do and identify your needs clearly to them.

Delegate certain tasks

Learning to delegate one or several tasks will help you to lessen the stress that you feel. Allow yourself the time you need to look after yourself.

To get the help you want, you must express your feelings as well as the nature of the support you expect.

Fact Sheet

Coping with the Diagnosis 3

There you are, the diagnosis has been made: your loved one suffers from a serious if not incurable illness. Everyone can experience a whole range of emotions. It's perfectly normal! Here are some situations you may face.

Fear of the unknown

This is one of the most difficult aspects to deal with. Some people react by conducting research to help re-establish a sense of order and mastery. The need to master the situation is a natural reaction in the face of fear.

Upsetting emotions

Your loved one can experience feelings of emptiness, sadness, horror, anger, panic, despair or helplessness. The best thing to do is to listen to them and to find someone to confide in.

Denial of the facts

Many people simply do not want to accept the idea of death, their own or that of their loved ones. Patiently help the person do what must be done to accept the illness and, ultimately, death.

"All battles in life teach us something, even those that we lose."

— Paulo Coelho

What to do?

- First, help your loved one to feel in control.
- If you judge that the timing is good, ask about their needs and desires.
- After the diagnosis, try to think about the next steps so that you can prepare for what is to come as a function of your needs and abilities. To help you, see Section 4 – Planning for the Future.

Questions that worry you

You and your loved one will have choices to make and questions that require responses, sometimes immediately, sometimes a little later on. You are probably asking yourself:

- How much time do we have left?
- How much pain and what symptoms will my loved one suffer and how can they be treated?
- Who can help us manage the situation and how will the family live through this loss?
- How can I care for my loved one and ensure their well-being?
- What shared decisions will help make the last stages of life the best possible?
- What options are available at home, in a private residence, in a long-term care facility, in a specialized establishment or in hospital?
- If that is what you prefer, will it be possible to remain at home until the end?

Helpful advice

- Listen carefully to your loved one.
- Remember that there are no good or bad feelings, nor good or bad emotions.
- Think about the role that you want to play with your loved one.
- Be frank, even if things don't work out the way they should.
- It is possible that your loved one will express strong emotions, even anger, that may involuntarily be directed at you.
- Take advantage of the good times. Use the time you have left to think about your life together and settle unanswered questions. If need be, have another person present that you are both comfortable with.

How do you help a loved one accept death?

You can support them in their steps to:

- Put their affairs in order
- Record family anecdotes
- Write letters
- Gather souvenirs
- Assemble family photo albums

Above all, don't forget to find ways to help yourself accept the death of a loved one.

The English Caregiver Helpline is there to provide you with resources
1-855-852-7795

Psychological help

In 40% of cases, the diagnosis of a terminal illness is accompanied by serious depression, unleashed by the illness or as a side effect of prescribed medication. Invite your loved one to consult a psychiatrist, a clinical psychologist or a social worker.

For the person who is dying, appropriate professional help has proven to be very useful for both affective and physical well-being. It is important to treat pain in the soul (sometimes called heartache) and physical pain at the same time.

Some Signs of Depression

- Chronic sadness
- Lack of energy
- Sleep or eating disorders
- Frequent crying
- Withdrawal from others
- Suicidal thoughts

You can't afford private psychotherapy services?

Don't hesitate to contact your CLSC to learn about the services they offer. In certain places, community psychotherapy clinics also exist and they can provide lower-cost professional services.

Section 2
Preventing Burnout

Despite their own professional, personal and family demands, caregivers often assume a range of responsibilities related to the person needing care. This underlines the importance of creating a solid support network in order to preserve their own physical and mental health.

Collaboration, which can be accomplished at many levels, is an essential element. In addition to immediate family and friends, other people can also contribute to the daily care needs.

Suppliers of health services and members of the community can also be part of the support team. If you don't call on them for help you deprive yourself of their expertise and their different points of view. The knowledge shared by all the members of the support team leads to a better understanding of the situation and opens paths to solutions that better respond to the vast range of needs of the person being cared for. It is an excellent way to avoid burnout.

Fact Sheet

Creating a Family and Community Support Network

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In many cases, the primary caregiver assumes many responsibilities in relation to the person being helped. A single individual in the family frequently takes on the entire load. However, in the long term, the only way to maintain your physical and mental health is by creating your own support network. This can include the following:

- **Family and friends**
- **Healthcare workers**
- **Community groups**
- **Private businesses or self-employed workers**

The key to successful involvement

To properly plan support for the person needing care, family members must collaborate with a variety of other people. Integrating all the partners and their expertise is a win-win formula for both the person needing care and the caregiver.

Who are they?

Groups that offer health services and members of the community can be part of the support team. They add their knowledge and their competence to the devotion and compassion of family members, friends and neighbours.

Advantages of a support network

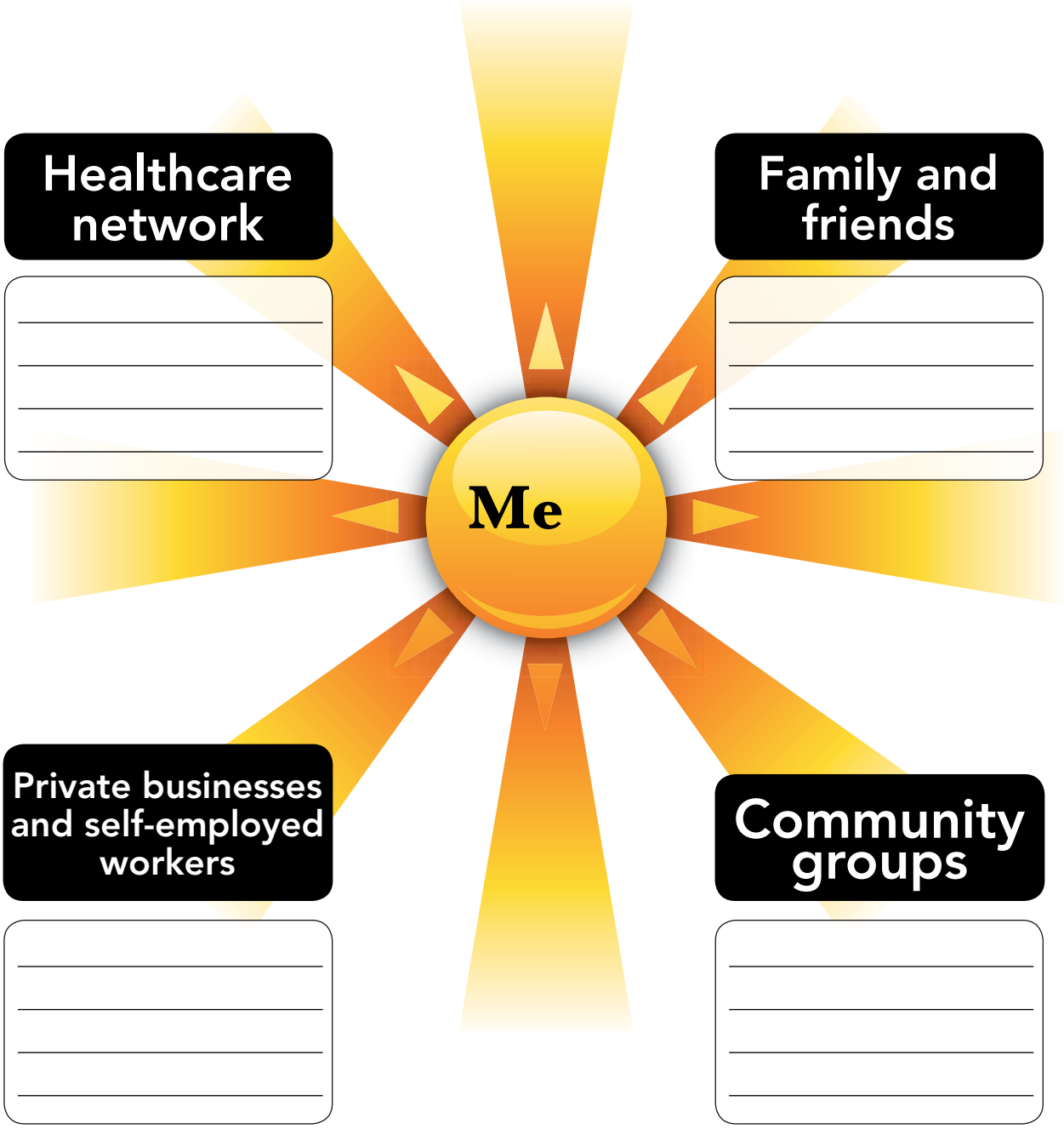
Creating a network to better respond to the needs of the person in care offers many advantages. It becomes easier to:

- develop organizational strategies for the members of the support team.
- make collective decisions.
- ensure the participation of all members of the support team.
- share the responsibilities so that all members of the support team are jointly responsible for carrying out the support plan. This will make it easier to ensure good communications.

You can get help from someone acting as a conciliator whose neutrality will assist the family and the person requiring care to share necessary information and the need for help. Get information from associations related to the illness you are dealing with.

A tool to help build your network

Fill in the boxes below to help identify your support network. By doing this, you will add rays to your sun.



"I am not a superhero, I only need a good network!"

— Yvon Boutin

Fact Sheet

L'APPUI: Caregiver Support Group

5

L'APPUI POUR LES PROCHES AIDANTS D'AÎNÉS
LAURENTIDES

English Caregiver Helpline 1-855-852-7795
(Toll Free)

L'APPUI Laurentides pour les Proches Aidants d'Aînés (Providing support throughout the Laurentians for caregivers of the elderly) is a non-profit organization that provides evaluations and financial support to local groups who offer respite, information, psychosocial services and training sessions. L'APPUI also offers a professional helpline which provides listening, information and referral services adapted to the needs of caregivers. The toll-free English helpline is 1-855-852-7795.

"The only gift is a portion of thyself."

— Ralph Waldo Emerson

A useful resource

The Caregiver Helpline is a personalized resource for caregivers to the elderly. The caregivers' counsellor is qualified to listen to you, to provide you with information and to refer you to services that meet your needs.

What is the Caregiver Helpline for?

The goal of this helpline is to accompany and support caregivers in their tasks, through their entire journey, as well as directing them to available community resources. By calling the Caregiver Helpline, you can:

- have access to psychosocial support when you call, if, for example, you feel overwhelmed by events;
- be directed to resources close to where you are, be they for respite, domestic help services, information, psychosocial support or any other specific need.

To learn more about the mission of L'APPUI, its values and the services it offers across Quebec, visit their website at ***www.lappui.org/english***

Fact Sheet

Recognizing the Symptoms of Burnout

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Caregivers must sometimes deal with periods of exhaustion that render them fragile and vulnerable. Created by ALPA, a Laval association of caregivers, the following exercise can help you to identify your own personal alarm signals. Learn to recognize them.

Although it is normal to sometimes experience these symptoms, when they become too frequent they may lead to undesirable behaviours (impatience, tone of voice, brusqueness, hurtful words, etc.).

Turn on your little RED LIGHT…

"One of the great kindnesses in life is that man cannot really help his neighbour without helping himself."

— attributed to Ralph Waldo Emerson

The Fatigue Barometer

Sign of fatigue	Rarely	Some-times	Often	Most of the time
I have difficulty falling asleep or I wake up often during the night.				
I wake up tired and lack energy to get through the day.				
I've lost my appetite or I eat too much.				
I am out-of-sorts or sick more often than before (flu, cold, headache).				
I take more and more medications.				
I feel irritable and impatient.				
I do a lot but, at the same time, I feel guilty for not doing more.				
I have trouble concentrating (making a to-do list, paying bills, reading, etc.).				
I tend to forget simple and familiar things (telephone numbers, names, keys, etc.).				
I've given up activities that I enjoy.				
I no longer have much contact with anyone but the person I'm caring for.				
I feel like I burst into tears over nothing.				
I feel sad and discouraged.				
I am anxious about the condition of my loved one and when I think of the future.				
I feel like quitting everything.				

If you have checked "Often" or "Most of the time," it is time to ask for help from your doctor or other members of the health and social services network.

References: Guide d'accueil, Intentions des personnes aidantes, Hôpital général de Montréal et Centre hospitalier de Verdun

Guide d'accompagnement à l'intention des personnes aidantes, Association lavalloise des personnes aidantes (ALPA)

Fact Sheet

7 Ways to Avoid Burnout

Don't be afraid of words: over time the state of the person you are caring for may deteriorate, even though you take on more and more caregiving responsibilities. So, are you condemned to exhausting yourself in turn? Of course not! As proof, this fact sheet offers you a range of ways to avoid burnout. To summarize:

- **Give yourself the time to recharge your batteries.**
- **Allow yourself those little pleasures that help you re-energize.**
- **Take time for yourself every day, and put it into your agenda.**

"You cannot prevent the birds of sorrow from flying over your head, but you can prevent them from building nests in your hair."

— Chinese proverb

Physical ways

- Take a nap.
- Look after your houseplants, garden.
- Do some manual labour: odd jobs, cooking, knitting, drawing.
- Take a walk, do some physical activity.
- Practice relaxation techniques, do yoga.

Psychological ways

- Sign up for a recreational activity offered by your municipality or by a community organization.
- Read an interesting book.
- Lose yourself in a piece of music.
- Go to a show, an exhibition, a stimulating lecture.

Social or spiritual ways

- Participate in mutual aid and support groups for caregivers.
- Go visit friends.
- Immerse yourself in a soothing activity such as prayer or meditation.
- Simply do what gave you pleasure before you were a caregiver.

When we are too tired, our help becomes less positive and the person in our care can feel it. The best way to help a loved one is to not become exhausted by the task…

Fact Sheet

Lifestyle:
Food, Physical Activity and Relaxation

8

As a caregiver, you take care of everything and everybody—to the point that you are seen as a superman or superwoman. But there is always another side to the coin: Is your life as a superhero exhausting you? Probably. Don't despair; here is some advice to help you stay healthy, in the following fields:

- **Physical activity**

  A healthy spirit in a healthy body—and a caregiver in better condition.

- **Food**

  We are what we eat. Healthy and balanced meals contribute to raising our energy level.

- **Relaxation**

  Stress saps a lot of energy. Knowing how to relax and loosen up is another way of helping a loved one.

"We must be the change we want to see in the world."

— attributed to Mohandas Gandhi

Did you know?

People who look after a loved one have increased levels of cortisol* and produce fewer antibodies. According to studies, this stress on the immune system is inversely proportional to the level of support provided.

To lower stress

Here is some healthful advice to help you better deal with this stressful period.

Rest and sleep

To provide your body with the rest and recuperation it needs, it is recommended that you sleep at least 7 hours a night. If you got less than that or you didn't sleep well, when possible take some time to rest during the day.

Physical activity

Movement contributes to strengthening immunity. It is also a good way to take some time for yourself, which also decreases your stress level. Find more details in Section 2, Fact Sheet 9.

Vaccination

During flu season, get vaccinated and invite your circle to do the same. Since the flu vaccine provides protection for a 6- to 12-month period, it must be repeated every year. This protection can help you avoid serious complications (pneumonia, bronchitis, sinusitis, ear infections and complications that can lead to death).

Food

A healthy lifestyle requires learning to take pleasure in, and care of, oneself. Dining enjoyment is an excellent way of combining the useful and the pleasurable. Find many useful ideas in Section 2, Fact Sheet 10.

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* Cortisol primarily allows an organism's energy reserves to be released. This is how it is involved in the reaction to stress.

Fact Sheet

Keeping Physically Active

9

With our full schedules, physical activity often drops to the bottom of the priority list. However just a few minutes a day of moving around more is all it takes to get in shape. Being more active also gives you more energy for taking care of a loved one.

Advantages of physical activity

- Better stress management and lowering of the negative effects of chronic stress on health.
- Strengthening of immunity and reduction in the frequency of infections.
- Improvement in blood glucose and cholesterol levels.
- Lowering of blood pressure.
- Reduced risk of developing cardiovascular diseases, diabetes and certain kinds of cancer.

"What we face may look insurmountable. But I learned something from all those years of training and competing. What I learned is that we are always stronger than we know."

— Arnold Schwarzenegger

How do I start?

Step 1

If you are totally sedentary, increase you physical activity level gradually.

Move often, it doesn't matter for how long or how strenuously.
The idea is to take advantage of each little opportunity to move.

Step 2

To make the maximum gains, move around regularly, ideally every day. Aim for 30 minutes of activity per day. You can build up to that over several weeks. You can divide this total into several periods of at least 10 minutes each (three 10-minute or two 15-minute periods per day).

Then increase the intensity of your exercises: moderate activity raises the heart rate and causes mild breathlessness. Rapid walking is an excellent exercise that can be done anywhere and takes no special equipment. With appropriate clothes, you can walk year-round. As a bonus, you get fresh air and that's great for your morale!

Adapt your physical activity to the season, the shape you're in, the time you have available, your current tastes, what is available nearby. By choosing activities appropriate to your situation you maximize your chances of persevering. If you have someone to relieve you, take advantage of your moments of respite to move (a walk in the park, yoga, cycling, cross-country skiing, etc.).

Step 3

You want to do more? Increase the length, frequency or intensity of your activities (one element at a time). Muscle-strengthening exercises improve your strength and endurance. The work involved in doing things with the person you are caring for, like assisting mobility or in the bath, will thus seem easier and you will reduce the likelihood of injuring yourself.

Useful advice

Set realistic and attainable goals in the short term. Once you have achieved your first objective, reward yourself and set another goal. That will help you stay motivated.

Simple and clever ways to increase your activity level

- Park far from the entrance to the shopping centre.
- Avoid escalators.
- Walk during your lunch hour.
- Exercise in front of the television during commercial breaks in a program or movie.

A kinesiologist is a health professional who specializes in physical activity, who uses movement for the purposes of prevention, treatment and performance.

www.kinesiologue.com *(website is French only)*

Fact Sheet

10 Eating Well

When we lack energy, neglecting proper nourishment is a risk. Unfortunately, overloaded work schedules, people to look after and frantic errands to run sometimes lead us to make less thoughtful food choices, and frequent dehydration can accentuate fatigue and send false hunger signals. To better fulfill your role as a caregiver, it is important to eat well and stay properly hydrated.

- **A question of health**

  Eating well helps to prevent cardiovascular diseases, Type 2 diabetes and certain types of cancer.

- **A question of energy**

  Healthy eating means more energy and better means of coping with stress.

- **A question of balance**

  Eating well means achieving a good overall state of health and well-being that is reflected in everyday life.

Join a collective kitchen; you will be able to prepare healthy meals while connecting with other people.

Why should I eat well?

Healthy eating provides many advantages, including:

- improving your ability to fill your needs for vitamins, minerals and other nutrients in order to avoid nutritional deficiencies;
- reducing the risk of obesity or excessive weight loss;
- having more energy, aging better, learning better, working more efficiently, better resisting the various stresses of your environment;
- achieving a good overall state of health and well-being, to take care of yourself as well as you take care of others.

Improve your health: ideas for eating better

Our food must be rich in nutrients to meet our nutritional needs, which rise during periods of stress. It is a good idea to follow, among others, the recommendations in Eating Well with Canada's Food Guide. This is basically what it recommends:

- It is preferable to use lower-fat dairy products, leaner meats and legumes.
- Choose foods high in dietary fibre.
- Use greater quantities of whole grain cereals as well as fruit and vegetables.
- Limit consumption of refined sugar.
- Lower consumption of caffeine (coffee, cola, chocolate).
- Drink lots of water every day.
- Minimize consumption of fatty and fried foods.
- Avoid skipping meals, and eat on a regular schedule.
- Consume fruits and vegetables at every meal, preferably unpeeled fresh ones for additional dietary fibre.

To learn more about Canada's Food Guide and to find menu suggestions based on your particular criteria, consult the following sites ***www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php*** and ***www.soscuisine.com/?sos_l=en!***

Fact Sheet

Breaking Out of Isolation 11

Fear of the illness afflicting the person being cared for can cause the people around them to be in denial or to avoid them, not knowing how to react to this unfolding situation. Some react by distancing themselves or by leaving. As a result, because it sometimes seems difficult to find help, the caregiver too often feels isolated when they choose to remain alone with the one being cared for.

Everyone has a responsibility

If prolonged, living in isolation risks damaging your health and your ability to help someone else. Everyone must learn to break out of isolation.

Learn to recognize your limits

The first step often consists of recognizing your own limits. Asking for help is not a sign of weakness but of maturity.

"Alone we go faster, together we go farther."

— Anonymous

The responsibility you carry

If you remain alone you run the risk of exhaustion, of becoming sick and no longer being able to take care of the person who needs help. It is incumbent upon everybody to take the necessary steps to break out of isolation.

A sign of maturity

Recognizing your weaknesses, vulnerabilities and limits of competence is a first step towards breaking out of your isolation. Far from an admission of weakness, it is, on the contrary, a significant indicator of maturity. Accepting that it's not possible to do it alone is the first stage of a process that will allow you to seek help. By building a better support network with those around you, you will be much less alone.

Existing resources

- Dare to approach support groups.
- Participate in conferences and training sessions aimed at caregivers.
- Consult your CLSC.
- Ask organizations and associations what services exist for help and support. Also visit the L'APPUI Laurentian caregivers' support website at http://www.lappui.org/english.

Call the English Caregiver Helpline

toll-free at

1-855-852-7795.

Don't remain alone…

Fact Sheet

12

Relations with Family and Friends

Sometimes caregivers feel all alone with the responsibility for the person needing care—because the family is absent, because they are by nature responsible, or simply out of sympathy and love. While it is gratifying to care for someone, it is also normal to feel emotions that cause us to question ourselves.

The sandwich effect

Often caregivers look after an elderly person at the same time as taking care of their own children. It is a heavy load…

A cocktail of emotions

Despite gratifying moments, you will inevitably experience feelings of sorrow, anger, or guilt… That's entirely normal.

"A man wrapped up in himself makes a very small bundle".

— derived from Harry Emerson Fosdick

A cocktail of emotions

When we see a loved one's autonomy slowly decline, we inevitably ask ourselves questions about the future. Fatigue and stress sometimes complicate relations with family and friends and make us run through the whole range of emotions.

Here are a few of them:

- Sense of heaviness, feeling the burden of the "sandwich generation"—having to care for an aging parent while juggling a job and raising one's own children.
- Anger regarding the evolution of the relationship and the new role as caregiver.
- Frustration at realizing the inability to respond to all the needs of the person being cared for.
- Guilt at feelings of not doing enough or of not making the right decisions.
- Sorrow when facing the loved one's loss of abilities and an impression of a lack of compassion from the family.

What to do?

Don't remain alone with your discomfort. Talk to a friend, a therapist or someone in the field.

The person you confide in will help you to see the possibilities of escaping this state of helplessness.

Get information from various groups, associations or companies linked to the illness of the person you are caring for. In certain cases you can get the help of a someone to act as a conciliator, whose neutrality will help the family, and especially the person receiving care, to better convey the necessary information and the need for help.

Fact Sheet

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Psychological Help

You don't have to be in a state of crisis to receive psychosocial treatment. Many options are available to you in order to balance your mental health and to better manage your role as a caregiver. Benefiting from psychological support, individually or in a group, is a gift to give yourself when you feel the need.

Accessible help

Whether you go through your CLSC, community groups or professionals in private practice, you have access to numerous resources that can provide you with support.

Support and information

Despite gratifying moments, you will inevitably have feelings of fear, doubt or discouragement. You must never hesitate to call on existing resources that can provide you with support and information.

Whether through conferences or peer-group meetings, CLSCs and community groups offer various means to support and inform you.
Consult them!

Asking for psychological help is not a sign of weakness, quite the contrary. Having the wisdom to consult without waiting for a crisis situation shows a healthy emotional balance. An ounce of prevention is worth a pound of cure!

Types of therapists

Whether through the psychosocial services of your CLSC or in a private office, you can consult a psychologist or a psychotherapist. However, depending on your preferences and your needs, other types of therapists including naturopaths and life coaches can provide you with counselling.

Other forms of help

Some CLSCs and community groups offer support and information meetings for caregivers, including lectures relating to the reality of caregivers' experiences. Many subjects on those themes are presented and everyone is free to show up for those that are of interest to them. A few minutes are generally devoted to the sharing of daily concerns.

Here are some examples of subjects that can be covered:

- Exhaustion
- Legal aspects
- Medication
- Healthy lifestyles
- Sleep quality

- Financial aspects
- Mourning
- Depression
- Government and community services
- Abuse and negligence
- Acceptance of the loss of autonomy of the person being cared for

In case of emergency

If you are exhausted or in a crisis situation, all you have to do is call the one-stop access desk of your CLSC to get support. A caseworker will take your request and evaluate your needs in order to guide you to the best resource.

You can also call 8-1-1.

Every reason is a good reason!

Many situations are urgent—the stress felt by a caregiver is never routine! Don't hesitate to communicate with the social worker always available at Info-Santé at 8-1-1: call if you have just received a diagnosis, call during a crisis situation such as wandering by the person you are caring for, call because of grief caused by the loss of autonomy or a death. In all cases, a social worker can listen to you and help you work through this crisis.

*Visit **www.ordrepsy.qc.ca/en/index.sn***
to learn more about psychologists and psychotherapists, or call the
Caregiver Helpline toll-free at 1-855-852-7795
*or visit their website **www.lappui.org/english***
for referral to an appropriate resource.

Section 3
Organizing Daily Life

Fact Sheet

Guide to the Needs and Habits of the Person Being Cared For

14

One of the major concerns for you as a caregiver is knowing who can take over in your absence. For that reason, we are providing you with a tool to help you determine, target and explain the needs and how the person in your care communicates with others, as well as the appropriate tasks your replacement can take on to provide the necessary support.

A tool for the person providing you respite

Carefully fill in the form that follows, to the best of your knowledge, if possible in the company of the person who will replace you. This will simplify relations with your respite person, who will be well informed about all the pertinent details of the daily life of the person being cared for. Once the form is filled out, all the information necessary to look after the person being cared for in your absence will be close at hand.

A tool that can be adjusted to fit

Don't hesitate to adapt or modify the form according to your particular needs, and as they change, so that the person who relieves you is always well informed. It goes without saying that this tool is particularly useful when the person in care has cognitive difficulties or aphasia and can't express their own needs.

Guide to Needs and Daily Habits

This document will help you pass on information in case of a temporary or permanent move into a care facility or in the event of an emergency or hospitalization.

Important

Name of physician: _____

Phone number: _____

Name of clinic or hospital: _____

Name of social worker: _____

Phone number and extension: _____

How to contact me:

Name of primary caregiver:

Phone number: _____ or _____

Name of other caregiver to be contacted in case of emergency:

Phone number: _____ or _____

Identification and general information

Family name and first name of person in care: _____

Best name to use in addressing the person in care: _____

Address: _____

Date of birth: _____

Health insurance card number: _____

What was the principal occupation of the person in care, over the major portion of their life? _____

_____

State of health and medications

Clear description, as detailed as possible, of the current state of health of the person in care (attach the diagnosis, if available):

_____

_____

Is the person taking medication: ☐ Yes ☐ No

If yes, please fill in the following grid (enter the time for each dose where required)

Name of medication:	Morning	Noon	Evening	Mealtime	Bedtime
_____	☐	☐	☐	☐	☐
_____	☐	☐	☐	☐	☐
_____	☐	☐	☐	☐	☐
_____	☐	☐	☐	☐	☐
_____	☐	☐	☐	☐	☐

Does the person refuse to take medications? ☐ Yes ☐ No

If yes, what methods do you use to administer the medication?

_____

Does the cared-for person show side effects?

_____

Aside from medications, is other care required (various injections, dressings, allergies or other)?

Details: _____

Communication

The person in care has difficulty recognizing:

☐ Where they are ☐ The time of day ☐ Dates ☐ People

☐ Other: _____

The person in care no longer remembers things from:

☐ A few minutes ago ☐ Last month ☐ Several hours ago

☐ Last year ☐ Yesterday ☐ More than a year ago

☐ Other: _____

The person in care clearly expresses their needs: ☐ Yes ☐ No

If yes, how? _____

_____

Person's mother tongue: _____

Language generally used in a social context: _____

Does the person easily lose concentration? _____

What do you say or do to get their attention? (ex.: subjects to bring up or ways to get their attention) _____

In an unfamiliar place, the person most often is:

☐ Angry ☐ Sociable and at ease ☐ Frightened ☐ Fearful and/or anxious

☐ Other: _____

Is the person naturally more (check all that apply):

☐ Introverted/quiet ☐ Aggressive/impatient

☐ Extroverted/motor-mouthed ☐ Distressed

☐ Other: _____

Does the person in care understand instructions? ☐ Yes ☐ No

If not, how do you help comprehension? _____

Does the person exhibit difficulties with self-expression or speech?

_____

Does the person show insecurity in the face of change?

☐ Yes ☐ No

If yes, give examples of their reactions: _____

_____

Does the person suffer from fears or phobias?

Explain and detail possible solutions: _____

_____

Does the person experience hallucinations/delusions?

Explain: _____

Are there any words, subjects, names that should be avoided in their presence?

Explain: _____

Hygienic care

The person losing autonomy needs help/support to:

Take a bath or shower	☐ Yes	☐ No
Wash their hair	☐ Yes	☐ No
Comb their hair	☐ Yes	☐ No
Shave	☐ Yes	☐ No
Brush their teeth/dentures	☐ Yes	☐ No

Other personal care (make-up, jewellery, skin cream, perfume, etc.)

_____

Summarize the bath or shower routine (time, water temperature, how to get them there)

_____

Is the person in care afraid of water? ☐ Yes ☐ No

If yes, what are possible solutions? _____

_____

Is the person in care prudish?

Suggest possible solutions _____

_____

Food

Does the person in care:

Have food allergies/intolerances? ☐ Yes ☐ No

If yes, to what? _____

Take medication for any such allergies or intolerances?

(Details) _____

Have trouble swallowing? ☐ Yes ☐ No

Need help to eat?

☐ Using utensils ☐ Help cutting food _____

☐ Recognizing utensils

☐ Other: _____

Does the person in care have:

☐ A poor appetite ☐ An average (or normal) appetite

☐ A great appetite

☐ Other: _____

What are their favourite foods?

_____

Which foods do they like the least?

_____

Does the person in care eat snacks (where, when, what types of snacks)**?**

☐ Yes ☐ No

Do they control their appetite? ☐ Yes ☐ No

Explain: _____

Do you have to remind them of mealtime? ☐ Yes ☐ No

Details: _____

Sleep habits

Does the person have a particular bedtime routine (time, nightclothes, etc.)?

☐ Yes ☐ No

Details: _____

At bedtime, is a nightlight or other security measure necessary?

☐ Yes ☐ No

Does the person in care have difficulty sleeping anywhere besides their own bed? ☐ Yes ☐ No

If yes, do you have a solution? _____

Does the person suffer from the following problems?

☐ Insomnia ☐ Sleepwalking ☐ Nightmares

Other (details): _____

Does the person regularly take naps? ☐ Yes ☐ No

If yes, details (where, when, etc.): _____

Are there any other details about sleeping habits?

_____

Security and other details

Can the person receiving care be left alone?
☐ Yes ☐ No

Is there a tendency to run away? ☐ Yes ☐ No
If possible, specify (under what circumstances, how to bring them back, etc.):

_____

Does the person have a tendency to wander?
☐ Yes ☐ No

Locks are necessary on:
☐ Doors to outside ☐ Kitchen or bathroom cupboards
☐ Other (details): _____

Does the person in care smoke? ☐ Yes ☐ No

_____

Does the person need help to smoke (what type)?
☐ Yes ☐ No

The person has difficulty:

Lying down	☐ Yes	☐ No
Remaining standing unassisted	☐ Yes	☐ No
Remaining seated unassisted	☐ Yes	☐ No
Moving around alone	☐ Yes	☐ No
Using the toilet alone	☐ Yes	☐ No

Other (details): _____

_____

Information about the person being cared for

The person:

Wears glasses Details: _____	☐ Yes	☐ No
Wears contact lenses Details: _____	☐ Yes	☐ No
Uses a cane Details _____	☐ Yes	☐ No
Uses a wheelchair Details _____	☐ Yes	☐ No

Uses a hearing aid ☐ Yes ☐ No
Details _____

Wears a wig ☐ Yes ☐ No
Details _____

Has a dental prosthesis ☐ Yes ☐ No
Details _____

Uses a hearing aid ☐ Yes ☐ No
Details _____

Anything else to note: _____

_____

Leisure

What type of activities does the cared-for person prefer?

☐ Physical ☐ Manual ☐ Intellectual ☐ Cultural

☐ Other: _____

The person in care enjoys:

Reading ☐ Yes ☐ No
Preferred subjects: _____

Music ☐ Yes ☐ No
Type of music: _____

Television or radio ☐ Yes ☐ No
Preferred programs or stations: _____

Sports/excursions ☐ Yes ☐ No
What type? _____

Manual activities (sewing, drawing, etc.) ☐ Yes ☐ No
Examples: _____

Other interests: _____

Schedule of a typical day

Morning:

5 a.m.: _____

6 a.m.: _____

7 a.m.: _____

8 a.m.: _____

9 a.m.: _____

10 a.m.: _____

11 a.m.: _____

Afternoon:

Noon: _____

1 p.m.: _____

2 p.m.: _____

3 p.m.: _____

4 p.m.: _____

5 p.m.: _____

Evening:

6 p.m.: _____

7 p.m.: _____

8 p.m.: _____

9 p.m.: _____

10 p.m.: _____

11 p.m.: _____

Other information to note:

_____

_____

_____

_____

_____

_____

_____

_____

_____

Notes

Fact Sheet

15

The Health and Social Services Network – Homecare Support

People with declining autonomy who cannot get around and who have temporary or permanent disabilities have access to support services and personal care at home, offered by the CLSCs. The help provided can take different forms, according to your needs and those of the person you are taking care of. In this Fact Sheet, we will look at:

The role of the one-stop access desk* of the CLSC

The processing of an application

The variety of homecare services

* The name of this service varies across establishments and may appear as Accueil santé, Guichet d'accueil, Guichet unique, etc.

"If you want to lift yourself up, lift up someone else."

— Booker T. Washington

The first step in getting an evaluation of your needs is to phone the one-stop access desk of your local CLSC so that a caseworker can evaluate the situation and direct you to the appropriate resource to answer to your needs. Support is provided based on the following conditions:

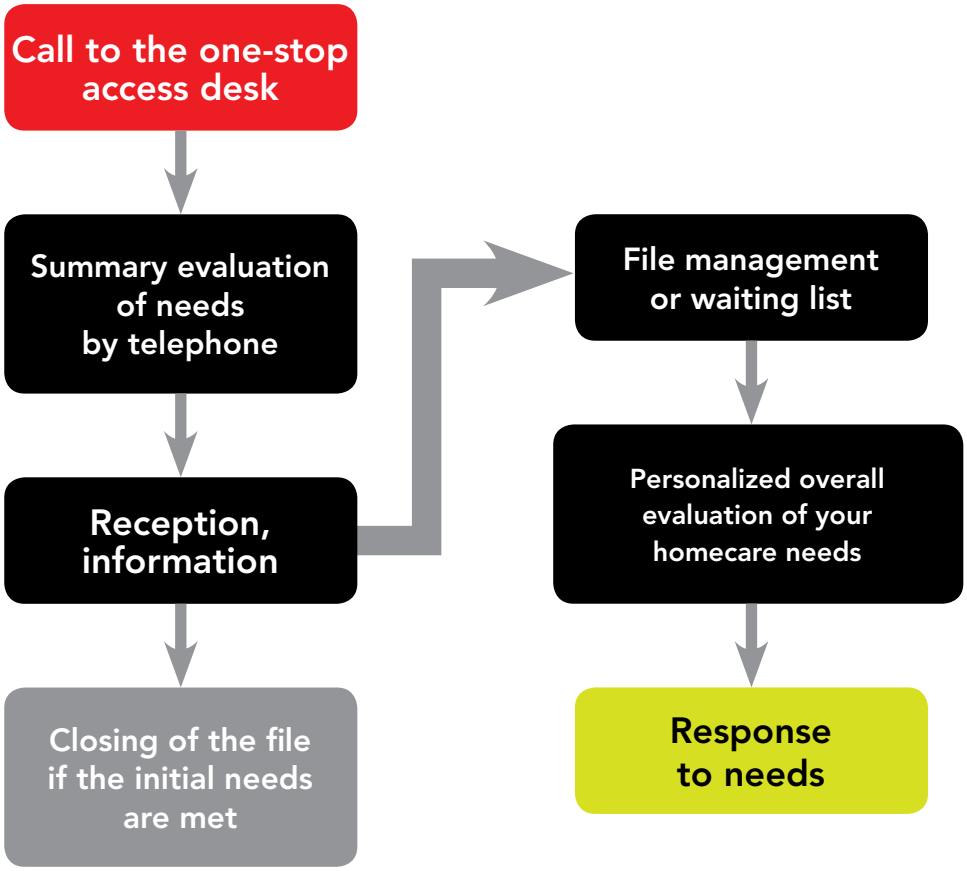
- age
- disability
- chronic disease
- surgery
- hospitalization
- a preterminal or terminal disease

The one-stop access desk of the CLSC

The key element for access to the services provided by the CLSC, the one-stop access desk plays the following roles:

- Reception and information for the person, their family, caregivers and all care partners.
- Referral to the appropriate service following the summary evaluation of the application.
- Systematically locating at-risk and vulnerable clients.
- Preventative telephone reminders to identified vulnerable people.
- Management of crisis situations in the home.

Processing of an application



Homecare support services

Access to homecare support services is subject to very specific criteria. To provide the full range of services, the CLSC may use domestic help social economy businesses, community organizations and volunteer groups.

Services offered by the Homecare Support department of your CLSC:

- Professional care and services
- Medical services (at home only)
- Nursing care
- Nutritional services
- Rehabilitation services such as physiotherapy and occupational therapy
- Respiratory care
- Psychosocial services
- Palliative care

Personal help services

Physical help services

- Hygiene care
- Feeding assistance
- Personal assistance

Domestic help services*

- Housekeeping
- Meal preparation
- Clothing maintenance
- Provisions

Services for caregivers**

- Personal assistance (training), planned supervision
- Respite, support, stimulation in the home for people with cognitive impairment
- Drop-in respite centre
- Respite beds in public care facilities
- Long-term respite at Le Baluchon
- Support for daily tasks
- Psychosocial services

Equipment loans

This service combines the loan of medical and specialized supplies, the loan of equipment, and the technical aids necessary to allow a person to remain or return to their home. The equipment is normally loaned on a temporary basis.

---

* Domestic help services are generally provided by domestic help social economy businesses.

** Services for caregivers may vary from one territory to another. Where they exist, some of the services listed above are provided by organizations in your area.

To obtain access to the various homecare services, contact your local CLSC.

In case of need outside normal business hours, please phone:

Info-Santé 8-1-1

Telephone consultation service with a nurse for medical questions or with a social worker for urgent situations such as crises, suicidal thoughts or other needs.

24/7

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Respite Services

The meaning of respite varies from one person to another. It can mean the time to run errands, garden, do paperwork, take courses, enjoy a sport, go out for a meal, or to visit family or friends. Some people simply need to stay home or to recharge their batteries away from the house.

First step

It is necessary to fully evaluate your respite needs. Various interveners can help you, from the Caregiver Helpline through community organizations to the CISSS.

Made-to-measure solutions

Depending on the circumstances and the available resources, respite can be provided at home, in a day centre or in a care facility.

"Help me or love me mean almost the same thing:
when we help someone, we love them, and when we love them, we help them."

— Philippe Labro

Respite at home

Respite at home aims to facilitate, encourage and prolong the ability of a person with declining autonomy to remain at home. It allows the caregiver to recharge batteries by participating in an activity of their choice while the person needing care remains at home, assured in their familiar surroundings.

However it is still difficult to find respite in the public or community network at irregular times (evenings, nights and weekends). In many cases private businesses, self-employed workers or private agencies must be called upon.

Respite in a day centre

Generally, day centres offer activities from Monday to Friday at times that vary by location. If attending such a centre at mealtime, a reasonably-priced meal may be available, as well as specialized transit service at minimal cost.

Temporary accommodation in a long-term care facility for a person in care

Usually lasting one or two consecutive weeks, this program provides respite to caregivers to help them out in a crisis situation or during a period of convalescence through the placement of the person being cared for in a long-term care facility. The objective is to contribute to a return home. This type of respite is offered as needed, for a defined period. In general, it must be reserved in advance. For a caregiver to take advantage of this service, a social worker must first evaluate the situation.

This type of respite also allows the person in care to become familiar with life in a care facility. If moving to a care facility becomes necessary, it helps make transition and adaptation easier.

Fact Sheet

Other Resources and Support Services

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Whatever your needs, other resources and services are available to you in your daily life as a caregiver. Sometimes it is enough to know which door to knock on to get help appropriate to your needs. Private resources complete the range of services available from the public and community networks.

Meals on Wheels

Simply eat well, and at a low cost!

Accompaniment and transport

Errands to run or doctor's appointments? Whatever, a volunteer can drive and accompany you. There are sometimes costs associated with this service.

Housekeeping cooperatives / Domestic help social economy businesses (DHSEB)

Maintenance of a house or apartment becomes demanding over time. A DHSEB can provide low-cost help, with rates based on your income.

"Real generosity when facing the future consists of giving your all in the present moment."

—Albert Camus

Meals on Wheels

An elderly person or one with declining autonomy, unable to prepare meals or leave home, can benefit from the services provided by Meals on Wheels, by paying some costs. Contact your local volunteer bureau, the Centre d'Action Bénévole (CAB) or your CLSC.

Accompaniment and transport

Accompaniment and transport service helps elderly people or those with reduced autonomy to get to their health establishments and to do their errands in a way that enables them to stay in their own homes. Contact your local CAB.

Housekeeping cooperatives / Domestic help social economy businesses (DHSEB)

Cooperatives and DHSEBs provide a variety of services such as housekeeping, major cleaning, seasonal chores or, in certain cases, personal assistance services. Based on the revenue of the person getting help, it is possible to receive a financial exemption. If you are younger than 65, contact your CLSC to get a referral from a social worker that will give you access to the exemption program.

Private services

Across the Laurentians, there are many other services that provide homecare or help in finding residences adapted to the elderly:

- Accompaniment/caretaking
- Personal and residential help
- Advice about accommodations

To find information on the various private businesses that provide services at home, use an Internet search engine with the following keywords:

- Remaining at home
- Homecare help
- Assistance for the elderly
- Accompaniment
- Respite
- Advice about residential facilities
- Friendly visits

The Caregiver Helpline is there to provide you with resources.
Call toll-free 1-855-852-7795 or visit their website www.lappui.org/english.

Fact Sheet

Accompanying a Loved One in a Hospital Setting

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For the average person, a hospital is an imposing physical presence and a complex organizational structure. That alone is enough to create stress! Also, it is easy to imagine the anguish and insecurity experienced by a person who may already be disoriented about where they are and why, and where their loved ones are. In many cases, the person no longer knows how to ask for help nor whom to ask. They search not only for their words but also for the meaning of them, and for how to begin their sentences. However, losing the means does not in any way reduce the needs. In this Fact Sheet, we will see:

The possible reactions and needs of the person being assisted

Knowing how the person being assisted reacts can help find ways to satisfy their needs.

The needs and approaches of the caregiver

The loved one's situation won't be the best if the caregiver is exhausted by the task. Tips for a more pleasant stay in the hospital.

How to get good service for the person being cared for

We all want the best for our loved ones. Here's how to get it!

Cognitive impairment: loss of bearings

At home, people suffering from cognitive impairment function by reflex and habit in familiar surroundings until a certain stage in the illness. However, in a new context, they can no longer get their bearings and their cognitive skills (remembering, understanding, reasoning) decline. The person will then turn towards the familiar face accompanying them to respond in their place. A heavy responsibility for the caregiver…

Possible reactions by the person being cared for

- Regression (greater loss of faculties, as if the disease is progressing rapidly)
- Aggressiveness or depression, insecurity, distress, insomnia…

Needs of the person being cared for and ways to help

- Above all, your loved one needs the warmth and reassuring presence of someone familiar, and acknowledgement of the legitimacy of their reactions (touch them, speak to them, smile at them).
- They must be accompanied by a person who will support them in exchanges with the medical staff. The caregiver thus becomes their memory for information received, capable of following up.
- When relying on external support, it is important to inform these substitutes of the dynamics and living conditions of the person being cared for. What are their habits, needs, tastes, fears? What are their relationships, their normal living conditions, their activities? Do they have pets? To help with this, use the Guide to the Needs and Habits of the Person Being Cared For that you will find in Section 3, Fact Sheet 14.

- It is important to keep the person being cared for informed, to situate them, even if it means constant repetition. This provides the person experiencing cognitive impairment with reassurance. (Remind them of where they are, why, since when…)

- The person being cared for needs to feel validated, and their morale kept up, by focussing on all that is working well (good vision, good hearing, the pleasure of eating, being in good physical shape…).

- The person with cognitive impairment likes to be talked to in the present tense in order to feel competent in these exchanges. Make the most of their senses: what they hear, what they see, what they smell (flowers, chocolate, heavily illustrated magazines).

- Humour is often intact among these people; it is a way to relax the atmosphere and make contact in an accessible way.

- It isn't necessary to be a specialist to lavish a massage on somebody. Often, a simple touch does it (a hand on the shoulder). However, remember that nothing is universal: some people are simply not comfortable being touched.

- Music can be comforting.

- Avoid stressful situations such as loud noises, bright lights or, on the other hand, lighting that is too dim.

Needs of the caregiver and actions to take

- The caregiver in it for the long haul must take care of their own needs. Sometimes it is better to do less, knowing that it can continue for longer. Our bodies have their limits, and so does our morale.

- One way to look after ourselves is to have help for the patient in the hospital (family, friends, neighbours, volunteers, community resources, or possibly private personal support workers).

- It is a good idea to identify a patient navigator to whom you can refer and who is able to create links between the different professionals (liaison nurses, social worker or pivot nurse).

- It is a good idea to be well informed about the illness and about the sufferer's possible reactions, the evolution of the disease, attitudes to adopt, methods that make things easier, using resources such as the Alzheimer Society, the CLSC, the physician.

Keep the Guide to Needs in Fact Sheet 14 close at hand.
It is an indispensable tool for the caregiver,
the one being cared for and everyone else concerned.

- In case of a dispute, various authorities can come to your aid: first the patient navigator in the file, the Users' Committee, the local complaints and quality of services commissioner, the CAAP (a community resource to support the lodging of complaints), the Quebec Ombudsman, the Human Rights Tribunal. For more details or possible avenues of recourse, see Section 5, Fact Sheet 34.

- Finally, this would be a good time to organize more support from various sources for the return home: the CLSC, the Alzheimer Society, the day centre, community groups, loved ones, and, why not, neighbours. Help can be provided at home and at the day centre to give some respite or to provide stimulating activities.

- In certain cases, the eventual move into long-term care can be considered. In order to make such a decision, it is a good idea to consult with professionals who are less emotionally involved in the situation. It is generally the job of the social worker to support you when making this decision.

At admission, what should you do to ensure good service?

If your loved one must be hospitalized, assure yourself that the pertinent information is properly noted in the file:

- Specify clearly that your loved one suffers from cognitive impairment so that everyone takes that into account in their interactions right from the start.

- Inform the personnel of the evaluations that have already been done. If there aren't any or the tests are not recent, ask that they be done.

Protocols exist on the use of restraints, isolation and chemical substances for the purposes of control. These interventions must be used ONLY if the patient represents a danger to him/herself or to others. It must all be recorded.

- Immediately upon arrival, state your expectations on the subject. If you refuse the use of these types of methods, specify the acceptable methods. (Refer to Article 118.1 of the Act Respecting Health Services and Social Services). If you cannot be reached rapidly and a situation demands it, the personnel will act and will inform you as soon as possible.

Inform the personnel about current medication, counter-indicated medications, if any, as well as known health problems.

- In many hospitals, patients are offered sleeping aid medication at bedtime. If these medications are unsuitable, ask that it be clearly indicated in the file.

- Specify all details concerning your loved one that have an effect on their health and well-being (ways to reassure, positioning, food intolerances, prostheses, adapted clothing, general habits, etc.).

Be as tolerant of yourself as you are of others, and don't expect perfection. But if unacceptable situations present themselves or persist, never tolerate bad service or a lack of respect for the ill person.

- Give an indication of the degree of autonomy (though it will be different at home and in the hospital). For example, does your loved one go to the toilet alone, accompanied, or wear incontinence underwear? Can they eat independently or only with help?

Testimonial

"Be vigilant! Remember that you must never be afraid to display your anxiety about your loved one while maintaining the goal of ensuring the well-being of a loved one in need. In principle, this is the desire of everyone involved. Your presence is a reminder of the need to work together with the medical team in order to facilitate their work, and your knowledge of your loved one will help ensure a reassuring hospital stay without too much difficulty. A sick person, with declining autonomy, deserves to be respected and to retain their dignity. The regressive attitude they display is simply a symptom of the loss of their faculties, their distress and their helplessness. At this stage, nothing remains but unconditional love."

—Denise Desmarais-Prud'homme

Daughter of a person with Alzheimer's disease in 2008. Revised in 2013.

Despite the quality of care offered, it is always important that the family monitor the file throughout the stay.

Notes

Fact Sheet

19 Ethical and Confidentiality Issues

The privacy law states that medical personnel cannot divulge information to a caregiver without the consent of the person being cared for.. However, the medical staff generally cooperates in the case of a person with declining autonomy.

A key role

Remember that you are the principal defender of the interests of your loved one within the health care team.

Lend an ear

As a frontline caregiver, listen carefully to what is said during medical visits. Take notes that you can refer back to later.

Prepare yourself for consultations

When you make an appointment with a doctor, specify the reasons for the consultation and what you hope to gain from it.

"Do what you can, with what you have, where you are."

— Theodore Roosevelt

How to prepare yourself for consultations

Despite questions of ethics and privacy, different ways exist to prepare for your loved one's various medical appointments and other procedures. Here are some of them:

- Make up a list of questions that you want to ask, in order of priority. Give a copy to the doctor.
- Keep an account or a journal of all care and treatment received. Write in information about the administration of medications and about appointments, the names of the members of the healthcare team and how to reach them, etc.
- As a caregiver, you are likely to notice changes and symptoms that might escape the notice of the healthcare team. If you see something, let the members of the team know.
- After the appointment, ask for a report or a summary of the diagnosis, if you think it will be helpful.

The average length of a medical consultation is 7 minutes.
This is sometimes not enough time to get answers to all your questions.

What to do?

If necessary, book a double or triple rather than a single appointment.

Fact Sheet

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Adapting the Home

When a person with declining autonomy lives at home, it is possible to receive support to adapt the home from Quebec's housing authority, the Société d'Habitation du Québec (SHQ). The program consists of financial aid paid to the proprietor of the home for the execution of admissible adaptation work responding to the needs of the disabled person.

For example, this can include the following modifications:

- Installation of an exterior access ramp
- Renovation of a bathroom
- Widening of doorframes
- Etc.

"I don't think you ever stop giving…
And it's not just about being able to write a check.
It's being able to touch somebody's life."

— Oprah Winfrey

Who can benefit from this program?

Any disabled person who has limited ability to perform daily activities can benefit from this program, on the following conditions:

- The person must provide an occupational therapist's report showing a significant and persistent deficiency, as well as disabilities that require modifications to the home.

- The person must not be eligible for any other financial aid for the adaptation of the home, notably under the insurance regulations of the Quebec automobile insurance corporation, the Société de l'Assurance Automobile du Québec (SAAQ) or the workers' health and safety commission (CSST).

Step 1

The first step is to get an evaluation from an occupational therapist. To do this, you must call the one-stop access desk at the CLSC to get a member of the homecare team to look after the application, or you can call a private resource.

If it is a matter of temporary adaptations to the home, you can look to the loan of equipment from the CLSC for a period of about three months. The occupational therapist will guide you towards the safest and easiest solutions for daily activities.

If home adaptations of a permanent nature are required, the occupational therapist will issue a report for the purposes of an application to the Home Adaptation for Seniors' Independence Program from the SHQ.

Step 2

After an analysis of the needs by the occupational therapist, a building inspector will visit the home in order to prepare the plans and specifications for the required adaptation. Work to enable the modification and adaptation of the disabled person's home so that they can enter, leave and have independent access to various rooms and to essential conveniences of daily life is admissible. The plans must provide simple and economical solutions and the work must be performed by a contractor who has the appropriate licence from the Quebec agency that oversees building contractors, the Régie du Bâtiment du Québec (RBQ).

Step 3

When the plans have been accepted, it is up to the family to request a quotation from a contractor licensed by the RBQ, and the contract will be authorized by the building inspector. In general, an application for the adaptation of a dwelling can be made once every five years.

To learn more about the standards and admissibility criteria, consult the website
www.habitation.gouv.qc.ca/english.html

Fact Sheet

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Principles for Safe Moving and Handling (PSMH) Training

For many years, workers in the health sector have helped develop solutions to safely move or reposition clients whose autonomy has been affected for any reason. Principles for Safe Moving and Handling (PSMH) training binds the health and safety of employees to that of clients. This training, adapted to the needs of caregivers, may be given by various organizations near you.

How to avoid injury

Providing daily support to a loved one can carry risks of injury. Learn great practical tips by participating in a PSMH training session for caregivers.

Moving about safely

As a caregiver, your own movement is inhibited so it is even more important that you learn the principles for safe moving.

Avoiding accidents

An accident, such as a fall, can happen at any time and create an obstacle to the help that you can provide. Give yourself the means to avoid accidents.

"A journey of a thousand miles begins with a single step."

— Chinese proverb

Training objectives for Safe Moving and Handling

There is no magic formula! Since there are as many different situations as there are people, the training is based on the principles of safety that guide the caregiver to making logical choices rather than on techniques that impose strict rules. After following this training, the caregiver will be able to accomplish the following tasks:

- Analyze the components of various situations involving moving people and take corrective action.
- Accomplish displacement tasks safely, according to the appropriate level of assistance.
- Choose safe and efficient methods in keeping with the possibilities and limits of the situation.
- Provide clear instructions adapted for the person being helped to optimize their contribution to the displacement.
- Share pertinent safety information with everyone involved.

*You can find a variety of publications on the **ASSTSAS** (Association for Health and Safety) website such as videos and information sheets on the principles for moving clients safely. You can also contact your CLSC to find out if PSMH training is offered to caregivers.*

Fact Sheet

22

Obtaining a Disabled Parking Permit

Every disabled person may have the right to a parking permit issued by the SAAQ. Available exclusively to a disabled person who drives a vehicle or to one who is a passenger, this portable permit must be suspended from the interior rear-view mirror of the vehicle only when it is occupying a reserved parking space.

What does this permit give access to?

A brief summary of the privileges that the permit provides.

Who can get one?

As a caregiver helping a disabled person, is it possible to get such a permit?

How to apply for one

A summary of the steps to follow to obtain this valuable permit.

"I've always respected those who tried to change the world for the better, rather than just complain about it."

—Michael Bloomberg

Important

If you have a permit, this privilege is given to you personally. It is not attached to a vehicle. You must use the permit only for your own personal needs.

You must always have the accompanying certificate with you. In addition, you do not have the right to loan it or to pass it over to anyone else.

What does this permit give access to?

Everywhere in Quebec, the permit allows access to reserved parking spaces for disabled persons having limits on their ability to walk. In municipalities, these parking spaces can be spotted thanks to signage recognized by the Highway Safety Code.

Who can get one?

To obtain a disabled parking permit, you must:

- have a handicap that results in a loss of independence or jeopardizes your health and safety in the course of travel for a distance that does not require the use of a means of transportation;
- submit, where necessary, an assessment showing that a disability has lasted at least 6 months.

How to apply for one

You must fill out the Disabled Parking Permit Application and return it, accompanied by an evaluation, if applicable, to the head office of the SAAQ.

Société de l'assurance automobile du Québec (ACT 6630)
Disabled Parking Permits
P.O. Box 19850, Terminus station
Québec, QC G1K 8Z4
www.saaq.gouv.qc.ca/en/miscellany/parking_permit/index.php

This form is also available at SAAQ service offices, on its Internet site as well as at Services Québec offices. You can also request one by phoning the Customer Relations Centre of the SAAQ:

Quebec City region: 418-643-7620

Montreal region: 514-873-7620

Other regions, toll-free: 1-800-361-7620

Cost of the permit

The cost is $16.20 (as of October 2014) to obtain the permit and the accompanying certificate, and it is the same cost to renew it. The permit is valid for a period of five years. Stickers specify the expiry date. Permit holders whose disability situation is temporary must request a re-evaluation of their situation at the date prescribed by the SAAQ in order to maintain the validity of the permit. Keep a photocopy of your application.

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The Specialized Transit Network 23

If your loved one is disabled and the disability greatly compromises their mobility, they may have the right to specialized transit services. An admissions committee will examine the application. Various sources of information exist, including the specialized transit service of your municipality, the regional specialized and public transit service, or the Ministry of Transport.

Conditions for eligibility

Specialized transit is not available to everyone… An overview of the requirements that give you access.

Recognized disabilities

Certain physical and cognitive disabilities qualify you to benefit from specialized transit.

Where to get more information

To find out more or to take advantage of the specialized transit services, there are various sources of information.

"The desire to go towards another, to communicate with him, gives rise in us to great energy and great joy, without any weariness."
—Dalai Lama

To qualify for specialized transit services, you must:

- be a disabled person, that is, "a person having a disability causing a significant and persistent inability and who is subject to facing obstacles to accomplishing daily activities."
- have mobility problems justifying the use of such a transit system.
- obtain a medical evaluation demonstrating the disability.

Recognized disabilities

The following disabilities are the only ones recognized that allow the right to specialized transit services:

- Unable to walk a distance of 400 metres on level ground.
- Unable to climb a 35 centimetre high step, or go down a step, without support.
- Unable to complete travel using public transit.
- Unable to find one's bearings in time or space.
- Unable to master situations or behaviours that may prejudice your safety or that of others.
- Unable to communicate verbally or with gestures, in addition to another disability.

Where to get more information

The specialized transit service in your municipality can send you the application form and specify the certificates required. If your municipality does not offer such a service, contact the specialized transit service closest to your home.

You can also consult the website of the Quebec Ministry of Transport at www.mtq.gouv.qc.ca. As of March 2015, there is no English available on this site. You can access the information in French by clicking on the Grand public tab, then on Transport adapté. You can reach the Ministry at:

Ministère des Transports du Québec – Review Board
Personal Land Transit Directorate
700 René Lévesque Blvd. East, 25th Floor
Quebec, QC G1R 5H1
www.mtq.gouv.qc.ca

Fact Sheet

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Modifying a Vehicle

Any person having a persistent disability that renders them unable to get into or out of a vehicle, or to drive in a safe manner, may be eligible for insurance coverage from the SAAQ. However, it must be necessary to modify the vehicle: to compensate for a situation of disability; to ease access to the vehicle; to allow its independent and safe driving; and the person must be recommended by an occupational therapist.

Costs covered for the modifying of the vehicle

This is not about getting a new paint job! Here's a look at what kinds of costs are covered.

Steps to take to modify a vehicle

When we know how to go about it, it's not so difficult to do. Follow the guide!

Responsibilities of the applicant

It is not a right, it is a privilege. You therefore have responsibilities.

"If destiny doesn't help us, we shall help it to come true."
—Khosrau I, King of Persia, 6th century

What you need to know

The passenger vehicle that you use for your everyday travel is the only one eligible for modification. In addition, only one vehicle can be modified, whether the person is the owner, long-term lessee or user of a vehicle owned by a family member (spouse, father, mother, member of the immediate family or of a foster family). If the vehicle is subject to a long-term lease, written authorization from the lessor is required before beginning to modify the vehicle. It is also now possible to acquire a factory-adapted passenger vehicle.

Costs covered by the SAAQ associated with modifying a vehicle

In general, the SAAQ will cover the lowest-cost solution appropriate to the condition of the person being helped. You can choose a more expensive solution on condition that you assume the responsibility and pay the additional costs. Here are the costs that are covered:

- Purchase and installation of the required and recommended equipment.
- Addition of equipment if the person's condition has changed since the original modification.
- Repair and replacement of authorized equipment, when these are no longer covered by guarantee.
- Required modifications to the body of the vehicle; mechanical verification of the vehicle after modification.

Steps to follow to modify a vehicle

The modification of a vehicle progresses in four steps.

1. Definition of the needs by an occupational therapist
2. Analysis of the solutions
3. Carrying out and verification of the modification
4. Training in the driving of the modified vehicle

Responsibilities of the applicant

- Inform the SAAQ of the intention to modify a vehicle.
- Collaborate with the representative of the SAAQ, particularly by carefully reading the documents supplied.
- Collaborate with healthcare professionals in defining the needs.
- Keep the disabilities in mind in the search for appropriate solutions.
- Confirm with the SAAQ that the vehicle is modifiable.
- Get authorization from the SAAQ before purchasing or repairing the equipment required for the modification.
- Choose the tenderers.
- Have the work done.
- Get guarantees from the suppliers.
- Be vigilant to ensure that the vehicle has the same platform as that for which the equipment recommendations were drawn up.
- Ensure the maintenance of the new equipment.

For more information, consult the SAAQ at the following site:
www.saaq.gouv.qc.ca/en/road_safety/vehicles/modified_vehicle/index.php

Section 4

Planning for the Future

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Legal and Judicial Aspects 25

When a person becomes sick, loses autonomy or dies, legal means are required to continue to look after their interests. Everyone can decide for themselves what should happen in regards to their personal care, their assets and their rights during their life or after their death. However, if nothing is done, the law provides for ways to act in their place.

The means of protection

The will, the power-of-attorney and the mandate in case of incapacity allow a person to choose how their interests should be looked after.

Three protection systems

When nothing has been planned, there are three protection systems: trusteeship, guardianship and tutorship.

"Men have the power to accomplish great things. They can build their lives, create others or help others to build their own."

— Thierry Cohen

The will

Taking effect only after your death, the will contains your wishes for the disposal of your assets. It must be written while you are in full control of your faculties. It can be written in front of witnesses, hand-written (holographic will) or before a notary. However, these options do not all have the same legal weight. The will can be changed at any time, as long as you still have all your faculties.

The power-of-attorney

Less known, the power-of-attorney is a mandate concerned only with assets. With the help of a power-of-attorney, another person is authorized to act in your place to accomplish certain ordinary administrative tasks (paying bills, withdrawals from a bank account). The person giving such a mandate decides when it begins and when it ends. This can be done in writing by two people or before a legal advisor.

The mandate in case of incapacity

Filled out by a person of full age with all their faculties (the mandator), the mandate in case of incapacity designates another person (the mandatary) to be responsible for the well-being, care, assets and rights of an individual who becomes incapable. All acts performed by the mandatary must be in the sole interest of the mandator.

- The incapacity must be established by doctors;
- A social worker must provide a psychosocial evaluation;
- The mandatary must have the mandate homologated by the courts, that is, have the need and conformity of the mandate approved before being able to exercise the powers that are provided for in it.

Did you know?

- You can name one or several people to be mandataries. For example, one person can be designated to look after your well-being and care and another can look after the estate and the rights of the mandator. If you have two children, it may be easy for you to decide…But nothing stops you from naming someone else.
- The mandate in case of incapacity can include instructions regarding the end of your life. For example, how to behave in the case of a treatment that will prolong your life without improving it.
- Forms exist to help you write your own mandate in case of incapacity. See the references listed at the end of this Fact Sheet.

Useful advice

Talk to your loved ones about the possibility of designating one or several of them as mandataries. That will make things easier when the time comes.

How to prepare it

Often prepared before a notary, the mandate in case of incapacity can also be written by the mandator him/herself. It must then be signed in front of two witnesses who are not involved in the mandate. In addition, the witnesses do not need to know what is in the mandate, only the authenticity of the signature of the mandator, and they acknowledge that all the mandator's mental faculties are intact.

Protective systems for people of full age

A person of full age who is declared incapable and who doesn't have a mandate in case of incapacity will be protected by legal regulations. Depending on the type of incapacity, it may be trusteeship, guardianship or tutorship. It is up to a loved one or the Public Curator to apply for the protective system, which will be instituted by the courts as a function of the needs of the protected person.

Trusteeship

Used when the incapacity is total and permanent, trusteeship is a protection system that is monitored and reviewed every five years. A private trustee looks after everything and has full power. When the Public Curator acts as trustee, the courts must approve certain limits of power.

Guardianship

This system applies in the case of partial or temporary incapacity. The courts must set the limits on the breadth of the powers of the guardian, which will be adapted to the needs of the person being protected. This protective system is reviewed every three years.

Tutorship

When the person losing autonomy still has their faculties but needs the help of a counsellor to accomplish certain acts, they are assigned a tutor. This concerns important acts such as the signing of a contract in the amount of several thousand dollars, or decisions concerning their well-being and care.

Note

In all cases, including the mandate in case of incapacity, the Public Curator keeps a public register where all protected persons are registered.

The estate assessment

In order to make the task easier for the person who must administer or liquidate your affairs, it helps to prepare an exhaustive list of your assets and liabilities. A notary can supply you with a standard form list or a booklet where you can list various information such as:

- Bank account numbers
- Insurance policies
- Investments
- Credit cards
- Will
- Funeral arrangements
- Income tax returns
- Subscriptions
- Pensions and annuities
- Real estate
- Vehicles
- Loans, etc.

Useful references

La Chambre des Notaires (Quebec notaries)

www.cdnq.org (site is French only)

The Quebec Law network

http://www.avocat.qc.ca/english/index.htm

The Quebec Public Curator

Montreal: 514-873-4074 Toll-free: 1-800-363-9020

http://www.curateur.gouv.qc.ca/cura/en/index.html

L'Institut de la Planification des Soins (care-planning institute)

http://planificationdessoins.org/ (site is French only)

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Government Financial Assistance Programs 26

Depending on the nature of your situation and the relationship you have to the person being helped, you may have access to one or another of the many government financial assistance programs available. But it is not always easy to find your way through this administrative maze. Here is an overview of the programs that are most popular or most helpful for when you are assisting a relative or someone with declining autonomy.

Tax measures

Many of the financial assistance programs are provided through the tax system. Your benefit will therefore come when preparing your tax returns.

Support for health needs

The Ministry of Health also offers some help. Those programs are often provided directly.

"The test of a civilization is in the way that it cares for its helpless members."
— Pearl S. Buck

Tax measures

Tax Credit for Home-Support Services for Seniors – Revenu Québec

The Tax Credit for Home-Support Services for Seniors is a refundable tax credit that gives you financial aid to make it easier for you to remain in your home. To be eligible for this tax credit in a given tax year, you must:

- be 70 years old or older;
- live in Quebec on December 31 of the year in which you received the services.

For details, consult the Useful Links in Fact Sheet 43.

When large sums are spent on remaining at home, it is possible to take advantage of an advance payment.

Domestic help services – RAMQ

The Quebec health insurance board offers The Financial Assistance Program for Domestic Help Services. This program allows you to get fixed or variable financial assistance which takes the form of a reduction in the hourly rate charged by a recognized domestic help social economy business.

Tax Credit for Caregivers – Revenu Québec

You can request a refundable tax credit for every eligible relative living with you in Canada in a home where you were the owner, tenant or sub-tenant, alone or with your spouse.

Tax Credit for Volunteer Respite Services – Revenu Québec

As a caregiver, if you have called on voluntary respite services, that person can benefit from a refundable tax credit on condition of having provided those services for at least 400 hours in the course of a year.

Financial support for health needs

Devices that Compensate for a Physical Deficiency – RAMQ

If you are helping a person with a mobility deficiency who must wear or use a device for their daily activities, these may be eligible for the Devices that Compensate for a Physical Deficiency Program designed for persons covered by the health insurance system.

Consult a doctor who will, if necessary, provide a written prescription detailing the need for a device because of the disability.

Free ambulance transportation for people aged 65 and over when medically or socially required – MSSS (Quebec ministry of health and social services)

This service covers displacements effected in Quebec from the home or a public place to the nearest and most appropriate establishment in the health and social services network, based on the type of care required by the patient's state of health. The emergency room doctor will authorize the free transport.

Tax credit for persons with disabilities

The tax credit for persons with disabilities is a non-refundable tax credit which can be used by authorized beneficiaries in order to reduce the amount of taxes payable. Every person who suffers from serious and prolonged mental or physical disabilities is eligible. This is the case when conditions force a person to significantly restrict their ordinary daily activities.

To apply, you must complete the tax credit certificate for a disabled person, on which one part must be completed by a qualified person, most often the attending physician. You can obtain the forms from a Canada Revenue Agency office near you, from Service Canada or on the Internet. **For more details, consult the Useful Links in Fact Sheet 43.**

Many other tax credits exist, for example: Tax Credit for Caregivers, Tax Credit for Volunteer Respite Services, Tax Credit Respecting the Housing of a Parent, Non-Refundable Tax Credit for Medical Expenses, etc.

How to apply

Ask a doctor to fill out the medical form (fees may apply). Ensure that the doctor includes a letter describing in detail the symptoms that interfere with carrying out "ordinary daily activities" for a sufficiently long period. In the case of mental illness, difficulty in "perception, thinking and remembering" capacities should be described. This letter is important as it serves to support the request.

You must also include your own letter describing, in your own terms, the impact of these symptoms on daily activities.

To learn more, visit the **Canada Revenue Agency website at www.cra-arc.gc.ca or contact Service Canada at 1-888-772-4673.**

Important note

Please note that the above information is correct as of October 2015. Note that a federal tax credit for family caregivers also exists. See the Useful Links in Fact Sheet 43.

Notes

Fact Sheet

Employment Insurance Compassionate Care Benefits

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If you must temporarily leave your work to provide care or provide support to a family member suffering from a serious illness that risks causing death, the government of Canada may allow you up to six weeks of compassionate care benefits.

Eligibility criteria

To take advantage of the program, you must respect certain admissibility criteria. Let's take a look at them…

Where to get information

It is always a good idea to be properly informed. Here is how to easily find all the pertinent information.

"The best portion of a good man's life:
his little, nameless unremembered acts of kindness and love."
— William Wordsworth

Compassionate Care Benefits

To take advantage of Compassionate Care Benefits through the Employment Insurance program, you must meet the following conditions:

- Have accumulated 600 hours of insurable employment;
- Accept to have your base weekly income reduced by more than 40%;
- Provide a certificate written by the physician attending the family member who needs the care or support, in which the doctor attests to the serious illness of the person and the risk of their dying within the next six months.

Where to get information

You will find answers to the most frequently asked questions on the website of Service Canada **www.servicecanada.gc.ca/eng/sc/ei/benefits/compassionate.shtml.** To find out more about Compassionate Care Benefits, you can call **toll-free 1-800-808-6352.**

Other programs offering tax advantages are available from the federal government, such as the Caregiver Amount. We suggest you consult a tax advisor or the Government of Canada website.

Fact Sheet

The Best Living Arrangements Possible

28

Inevitably, when we look after someone with declining autonomy, we must eventually deal with the best way to provide living arrangements adapted to their needs. Depending on the nature of their illness, state of health and degree of autonomy, various housing resources are available for the elderly who are losing autonomy or are ill. Essentially, these resources are divided into two main categories:

Housing resources in the private network

Depending on the level of autonomy of the elderly person, they may find themselves in a residence with services for the independent or semi-independent elderly.

Housing resources in the public network

Again, it is the level of autonomy that determines the most appropriate resource. It could be a family-style residence, a foster home or a long-term care facility (CHSLD). Private intermediate resources contracted to the public network also exist.

"No person was ever honoured for what he received.
Honour has been the reward for what he gave."

— Calvin Coolidge

The private network

A private residence is a multi-unit building where, in exchange for a rental payment, apartments or rooms are provided, along with a range of services principally related to safety and help with domestic and social life. These are divided into two categories:

- Private residences with or without services for independent seniors.
- Private residences with services for semi-autonomous seniors.

When the time comes to find new accommodations for your loved one, a housing counsellor can provide you with support and evaluate your needs in order to identify the type of accommodations required. This service is generally offered at no cost.

Strict regulations

Owners of seniors' residences that provide more than two services must obtain a compliance certificate in order to run this type of establishment. The Regulation Respecting the Conditions for Obtaining a Certificate of Compliance and the Operating Standards for a Private Seniors' Residence came into force on March 13, 2013. To learn about the conditions for obtaining a compliance certificate for a private seniors' residence, visit the site of the Quebec ministry of health and social services (MSSS) at

http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=3&file=/S_4_2/S4_2R5_01_A.HTM.

You can consult the list of certified private seniors' residences on the MSSS site at **http://wpp01.msss.gouv.qc.ca/appl/K10/K10accueil.asp (site is in French only)**

Low-Rental Housing (LRH)

LRHs are low-cost dwellings intended for low-income households. Aside from the rental income, LRHs are financed by the three levels of government: federal, provincial and municipal. Rental costs are fixed according to the By-law Respecting the Allocation of Dwellings in Low-Rental Housing. It provides for households to pay 25% of their total income, including the cost of heating. However the costs for electricity, parking, etc. may be in addition to this amount.

Community housing by non-profit housing organizations

The mission of a non-profit organization (NPO) for housing is to offer housing solutions adapted to the needs of households or persons making up their clientele. The residents are tenants in their units. The Board of Directors is made up of representatives of groups active in the neighbourhood and representatives of the tenants. Participation in democratic life by the latter is encouraged.

Housing NPOs can respond to a variety of needs, whether it is for seniors with modest loss of autonomy, young people in difficulty, people at risk of homelessness, or victims of violence. Depending on needs, many housing NPOs offer community support services.

Housing Cooperatives

A housing cooperative is an association of people whose mission consists of providing its members a service: access to appropriate accommodations at an affordable price. In a housing cooperative, all the members (the tenants) are involved in its management, according to democratic principles (one member, one vote). At its Annual General Meeting, the resident-members elect their Board of Directors, whose responsibility it is to see to the carrying out of the decisions taken and to coordinate the work of the various committees set up to ensure the daily functioning of the group (finances, maintenance, selection, site, neighbourliness, secretariat, etc.).

Housing resources in the public network

If staying at home is no longer possible for your loved one, the social worker from your CLSC will direct you to the public housing resource suited to their condition. Once again, several types of accommodations exist, depending on the degree of independence shown in an evaluation done ahead of time.

Family-type resource

A family-type resource is a foster home for adults and seniors. For example, it can be one or two people who take into their home a maximum of nine adults or seniors sent to them by a public establishment, to answer to their needs and provide them with living conditions as near as possible to their normal home life.

Intermediate resource

An intermediate resource (IR) is a person or corporation that owns or rents housing facilities. The IR is contracted directly to a public institution designated for this purpose by the CISSS. According to certain admissibility criteria, this resource houses those already registered in an establishment who need support or particular care. The resident remains the responsibility of the establishment. The IR offers an adapted living environment and the support services or assistance required. Professional services such as nursing care, psychosocial and rehabilitation services, among others, are provided by the homecare services of the CISSS.

A long-term care facility

Intended for adults with reduced functional or psychosocial autonomy, the long-term care facility (Centre d'Hébergement et de Soins de Longue Durée or CHSLD in French) takes them in for temporary or permanent stays. These

facilities provide accommodations, assistance, support and supervision as well as rehabilitation, medical, nursing, pharmaceutical and psychosocial services. Certain establishments also have day centres and day hospitals. These services are offered to adults and seniors who, because of their loss of autonomy, can no longer live in their own homes despite the support of their family circle.

Important note

Financial contribution by the resident

In the case of accommodation resources in the public network, the financial contribution of the resident is established according to the assets of the person being housed, without exceeding the current maximum based on the type of room occupied.
See Section 4, Fact Sheet 29.

Fact Sheet

Financial Contribution Program for Accommodated Adults

29

The financial contribution is the amount the government charges to adults who are accommodated in Quebec healthcare facilities. It addresses the concern that accommodated adults be treated equally to persons living at home.

To determine the contribution

Many factors are used to determine the contribution amount. Here's what's involved.

Calculating the contribution

After determining the elements needed to evaluate the contribution, calculations must also be made to take into account the individual's situation.

The goods and services provided

One of the first questions to ask is whether meals are included, and at what price. But what about soap, shampoo or laundering of linens?

"Life is a journey not a destination. There are no mistakes, only the risks that we have taken."

— Anonymous

A rule that creates fairness

In the same way as people who live at home, accommodated individuals must assume costs associated with their food and shelter. Since healthcare remains covered by the RAMQ, these costs are not included in the calculation of the financial contribution for accommodation.

To determine the contribution

To determine the contribution, two elements are taken into account:

1. The category of the room

The monthly cost of rooms varies according to whether it is a private room or contains 2, or 3 or more beds.

Category / Monthly cost (as of January 2015)

- Room with 3 beds or more: $1,112.40
- Semi-private room: $1,496.40
- Private room: $1,789.80
- In an intermediate resource: $1,184.70

2. Your ability to pay

These are the maximum rates. If you are unable to cover this amount, your contribution will be determined according to your capacity to pay, based on your income, assets, savings and family situation.

The RAMQ provides a simulation tool for calculating the financial contribution, available at www4.prod.ramq.gouv.qc.ca/Cah/BY/BYG_GereAdheb/BYG6_CalcContb_iut/BYG6_Accueil.aspx?LANGUE=en.

Calculating the contribution

- After admitting the person, the facility sends the RAMQ the properly completed form entitled Registration or Changes.
- The RAMQ then sends a notice to the accommodated person or their representative (with a copy to the facility) indicating the amount payable for the room occupied and the procedure to be followed if the person feels that their financial or family situation justifies a reduction in the amount of the contribution.
- The person pays the accommodation facility the amount shown on the notice from the RAMQ.

Can the accommodated person have the amount of their contribution changed?

- Yes. In order to do so, the form entitled Application for Exemption or for Re-evaluation must be filled out and returned to the RAMQ. It is available from the accommodation facility.

- The RAMQ then examines the application, taking into account the liquid assets, possessions, and the income of the person (and spouse, where applicable), as well as family obligations. Calculation of the contribution also takes into account certain deductions related to the personal expenses of the accommodated person, their spouse and dependent children, or for having to break a lease.

- A decision will be issued within 90 days of receipt of the re-evaluation request. If you are still not satisfied, you must appeal to the Tribunal Administrative du Québec. You have 60 days to do so after receiving the decision.

Who must contribute?

Every person aged 18 or over whose condition requires accommodation in a healthcare facility must contribute to accommodation costs.

When is the contribution payable?

Residential and long-term care facility

The contribution is payable as of the first day spent in the facility. The contribution is calculated as a function of the number of days of accommodation. The day of your arrival is included in the calculation, but the day of your departure is not.

Hospital providing acute care

If you are awaiting a place in a long-term care facility because your condition does not allow you to return home, the contribution is payable from the time that you are discharged from acute care. No contribution is required as long as your condition requires acute care. However, after 45 days you are presumed to be receiving long-term care. You will therefore be required to pay a contribution unless the doctor certifies in your medical file that your condition still requires acute care. This certification must be renewed every 30 days thereafter.

Goods and services provided to the accommodated adult by the facility

The goods and services provided by the facility are the responsibility of the MSSS, in accordance with circular 1995-010 issued on this subject.

The facility provides, free of charge:

a) Products and services necessary to personal hygiene, such as:

- paper products or other products indicated in the individualized service plan, or any other products required by the accommodated person's particular condition;
- skin creams, shampoo, deodorant, toilet soap, toothpaste and facial tissue;
- laundering and normal care of the person's linen and clothing. These tasks may, however, be performed by the person's family.

b) Any equipment used by an accommodated adult for therapeutic purposes.

Services provided, free of charge

Medical and nursing care, services provided by other professionals, and medications are provided free of charge when they are provided by the facility. (In the case of intermediate resources, the cost of medications is assumed by the resident.)

Goods and services that accommodated adults must pay for themselves

The costs of the following goods and services are the full responsibility of the accommodated adult:

- hairdressing services
- personal care products (cosmetics, hairspray, lotions, etc.)
- tobacco and newspapers
- meals ordered from outside
- a personal telephone, rental of a television
- special care of clothing (dry cleaning, mending, etc.)

The facility may pay part of the cost of dental and optometric care, as well as various technical aids (prostheses, orthoses and corrective footwear), on a scale based on the income of the accommodated person.

Before incurring any expenses, it is important to check whether the facility will accept to reimburse them.

For more information about calculating the financial contribution, visit http://www.ramq.gouv.qc.ca/en/citizens/aid-programs/Pages/accomodation-public-facility.aspx

You can contact the RAMQ directly at:

Régie de l'Assurance Maladie du Québec,
Direction de la Contribution et de l'Aide Financières
(contribution and financial aid directorate)

425 de Maisonneuve Blvd. West, suite 213
Montreal, QC H3A 3G5

Phone: 514-873-1529
Fax: 514-864-4179
Toll-free: 1-800-265-0705
Fax, toll-free: 1-800-308-0265À
TTY service for the hearing impaired, in Quebec City: 418-682-3939
TTY service for the hearing impaired, in other regions, toll-free: 1-800-361-3939

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It sometimes happens that a couple must separate financially for reasons beyond their control. If, because of illness, one member of a couple can no longer care for the other at home and is obliged to place the loved one in a public accommodation facility, the caregiver who remains at home may benefit from a fiscal measure called "involuntary separation."

Consequences for the person remaining in the home

When the spouse with declining autonomy is transferred to other accommodations for health reasons, what happens to the person who remains in the home?

How to proceed in order to benefit

What steps must be taken so that the revenues of the two spouses are calculated independently?

"It is not enough for a great nation merely to have added new years to life —our objective must also be to add new life to those years."

— John Fitzgerald Kennedy

To ease the fiscal burden

When the pension income of the spouse accommodated in a residence is paid almost entirely to the residence, there is a risk that the other spouse will end up in a difficult financial situation. Happily, thanks to Social Development Canada, the person remaining in the home will be considered as a "single person" due to involuntary separation, which then provides a Guaranteed Income Supplement. This income supplement will compensate for the loss of the revenue of the spouse in accommodations.

How to get the supplement

To apply, the spouse remaining in the home must complete two forms:

1. **Statutory Declaration – Separation of Legal Spouses and Common-law Partners;**

2. **Guaranteed Income Supplement or Statement of Income for the Allowance or Allowance for the Survivor**

More information on this topic can be found by contacting Social Development Canada or online at www.seniors.gc.ca

Fact Sheet

Adapting to the Change from Home to New Living Arrangements

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Looking after a loved one marked by old age, illness or disability can require examining the eventuality of new living arrangements. Despite the resources put in place, the situation can reach a level that exceeds the abilities of the caregivers.

Getting support

We can't say it often enough: it is impossible to do it all alone, even for the most dedicated of caregivers. This is even truer when it comes time to make a major change.

Proceed step by step

The change in living arrangements can upset anyone, more so when a person is already losing autonomy…

"We do not prepare ourselves for death. We detach ourselves from life."
— Paul Claudel

Getting support

When making this difficult choice, it is essential to get support, as much for the caregiver as for the person receiving care. A social worker from the CLSC will provide you with valuable support by accompanying you in this step. Their role consists of receiving you, listening to your concerns, your doubts and your expectations, as well as guiding you as you research living arrangements adapted to the needs of your loved one.

Step-by-step adjustment

The person receiving care is not always ready to imagine the change that confronts them when facing the end of their life: the loss of familiar markers, the changes to lifestyle, to daily rhythms and to surroundings. This transition requires time for adjustment, which leads to greater acceptance. Only then will the person in care and the caregiver both appreciate the benefits of the new accommodations.

A blessing in disguise

If the person you are helping leaves their home to live in a private residence, it is with the goal of better fulfilling their needs in order to compensate for certain disabilities, as well as improving their overall quality of life. It sometimes takes the person being helped a bit of time to fully appreciate this.

Proceed step by step

Before choosing new living arrangements for your loved one, you must first evaluate the residences and their services. It is important to ascertain the way the place is set up, the on-site services offered, nearby services and the quality of the welcome as well as the general atmosphere.

As much as possible, consider a gradual adjustment by using respite weeks in the long-term care facility. This step will enable the person in care to gradually adapt to the new environment and the family to adapt to the new reality.

Section 5

Increasing Your Knowledge

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Information and References about the Most Common Illnesses

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Aging and loss of autonomy are generally accompanied by degenerative diseases that complicate daily life. Although you can't possible predict or know everything, as a caregiver you will have greater power in dealing with the situation by getting as much information as possible about the most common illnesses. To be better able to face events, being informed is the key!

Cognitive impairment

From Alzheimer's disease to vascular dementia, cognitive impairments also include frontotemporal degeneration and Lewy body dementia.

Implacable enemies

When we talk about Parkinson's disease or cancer, we know they are implacable enemies. But what to say about chronic obstructive pulmonary disease (COPD), diabetes, strokes or aphasia?

"How lovely to think that no one need wait a moment,
we can start now, start slowly changing the world."

—Anne Frank

Cognitive impairment

Alzheimer's disease

Alzheimer's is the best known of cognitive impairments. In Canada alone, it is the most widespread neurodegenerative disease, with 64% of all cases. In general, Alzheimer's disease evolves through several stages, but no typical trajectory exists for the person suffering from it. The signs, the order they appear in and the duration of each stage vary from person to person. The disease generally progresses slowly, with the symptoms of different stages sometimes overlapping.

The consequences of Alzheimer's

This cognitive impairment is responsible for a progressive alteration of the memory, but also, depending on the case, of judgment, coordination, communication, attention span and orientation in time and space. Depending on the degree to which the individual is affected, many will need support to perform their daily activities: managing their budget, personal care, dressing, taking medications, etc. All these repercussions cause major upset to the person with the disease, but also for their loved ones.

Symptoms to watch for

In order to help you recognise the signs of the disease, the Alzheimer Society has prepared the following list of symptoms:

- Loss of memory interfering with daily activities
- Difficulty in executing familiar tasks
- Language problems

- Disorientation in space and time
- Reduced judgment
- Difficulties with abstract ideas
- Misplaced things
- Mood or behavioural changes
- Personality changes
- Loss of interest

Vascular dementia

The second most common type of cognitive impairment, vascular dementia shows up when the cells in the brain are deprived of oxygen. Generally, this disease progresses rapidly.

"Difficulties may happen in steps. Sometimes, the person's abilities may deteriorate for a while and then stand still for a time. Then, they may deteriorate again. The cognitive symptoms, the ability to think, may change, affecting some areas of the brain more or less than others (e.g., the areas that control language, vision or memory). Urinary difficulties (difficulty going to the bathroom) are common in people who have VaD." [1]

Frontotemporal degeneration

Usually appearing at a younger age than Alzheimer's, frontotemporal degeneration strikes men and women equally. People with this form of disease sometimes present symptoms such as sudden memory loss or behavioural changes, or they experience difficulty speaking or moving.

The person may undergo personality changes. They may show inappropriate social behaviour and can be easily distracted. They no longer understand their own behaviour nor that of others. Language difficulties are also often associated with this type of cognitive impairment.

Lewy body dementia

Normally, this type of cognitive impairment progresses rapidly. The person struck by this kind of dementia displays symptoms similar to those of Alzheimer's disease, such as the progressive loss of memory and reasoning, but also those of Parkinson's disease, such as muscular rigidity, tremors, bent posture and slow movements.

Depression and anxiety can also be present in the person with Lewy body dementia. In addition, they can be very sleepy during the day and wide awake at night. This cognitive impairment also causes frequent and recurrent visual hallucinations.

[1] Alzheimer Society of Canada, consulted October 21, 2014 at www.alzheimer.ca/en/

For more information on all these types of cognitive impairments, contact the Laurentian Alzheimer Society at 1-800-978-7881 or consult the website of the Alzheimer Society of Canada at www.alzheimer.ca/en/

Parkinson's disease

Parkinson's disease is a neurodegenerative disease that affects control of movement. The most common symptoms are tremors, difficulty walking, balance problems, and muscle rigidity. It is possible to live with Parkinson's disease for many years, but there is currently no available cure. A significant proportion of people with Parkinson's disease also develop cognitive impairments in the later stages of the disease.

For more information about Parkinson's, consult the website of the Parkinson Society of Quebec at www.parkinsonquebec.ca/en/home.htm

Cancer

Cancer is a pathology characterized by the presence of one or many malignant tumours formed through the transformation of an initially normal cell. Cancers are classified according to the type of cell in which the first transformation occurred; this first malignant cell then divided and formed the primary tumour. Some primary tumours progress towards a more global invasion of the organism, known as metastasis.

To learn more about the different types of cancer and their treatment, consult the website of the Canadian Cancer Society at www.cancer.ca/en

Chronic Obstructive Pulmonary Disease (COPD)

This is a long-term pulmonary disease, usually caused by smoking. COPD encompasses several pulmonary diseases, the most common being chronic bronchitis and emphysema. Many people with COPD have both these diseases. COPD is also known as Chronic Obstructive Bronchopneumopathy or COBP.

COPD slowly damages the airways (the tubes that allow air to enter and leave the lungs). People suffering from COPD have swollen airways that are partially blocked by mucus. The small air sacs at the end of the airways can also be damaged, making breathing difficult.

The main symptoms of COPD are coughing, secretion of mucus (sputum) and breathlessness. Doctors diagnose COPD with the help of lung tests. They use a simple test, called spirometry, to measure the amount of air that you can breathe out of your lungs.

Consult the website of the Lung Association at www.lung.ca

Diabetes

Diabetes is an incurable chronic disease caused by a body's inability to produce or to properly use insulin, which causes an excess of sugar in the blood. Produced by the pancreas, insulin is a hormone that allows human body cells to use glucose (sugar) contained in foods. The cells thus have all the energy they need to function.

If there is a lack of insulin or if it does not adequately fulfill its role, as in the case of diabetes, the glucose can no longer serve as a fuel for the cells. It therefore accumulates in the blood and is eliminated in the urine. Over the long term, hyperglycemia caused by the presence of excessive glucose in the blood leads to certain complications, notably affecting the eyes, kidneys, nerves, heart and blood vessels.

Still a mystery…

The true cause of diabetes still remains unknown. We do know that certain factors can influence the appearance of diabetes: heredity, obesity, pregnancy, certain viruses or certain medications. Two main types of diabetes exist: Type 1 and Type 2.

Variable symptoms

The symptoms of diabetes do not always present the same way or with the same intensity. Whether it is Type 1, Type 2 or gestational diabetes, it is necessary to consult a doctor. Here are the main symptoms:

- Fatigue, sleepiness
- Increase in the amount of urine
- Intense thirst
- Excessive hunger
- Weight loss / weight gain
- Blurred vision
- Slow healing of wounds
- Infection of the genital organs

- Tingling of the fingers or feet
- Personality changes

Sometimes symptoms are not visible. Diabetes is a severe illness that can have a considerable impact on the quality of life of those living with it.

Consult the site www.diabete.qc.ca/en

Stroke

A stroke is a sudden loss of brain function caused by the interruption of blood circulation inside the brain (ischemic stroke) or by the rupture of a blood vessel inside the brain (hemorrhagic stroke). These two phenomena cause the death of brain cells (neurons) in the affected region.

Did you know?

- The after-effects of a stroke depend on the location within the brain that is damaged as well as the breadth of the damage. A stroke can affect all kinds of functions, like the ability to move, to see, to remember, to speak, to think, to read and to write.
- Sometimes damage to the brain resembling that of a stroke can result when the heart stops beating (cardiac arrest). The longer the brain lacks oxygen and the nutrients brought by the blood, the greater the risk of permanent damage to the brain. This problem is usually called an acquired brain injury.

Aphasia

Relatively unknown to the general public, aphasia affects many people in Quebec (4,000 new cases per year) and around the world. Nonetheless, many people with aphasia live in the shadows, in isolation. That is why raising awareness of aphasia is so important.

Aphasia is the partial or total loss of the ability to communicate by a person who, in the past, was able to speak normally. It can affect the ability to speak, to write, to calculate, and, in certain cases, the ability to understand a written or spoken message.

Communication difficulties

Basically a language problem, aphasia is expressed in a variety of difficulties in expression or comprehension, both orally and in writing. The aphasic person does not necessarily show any physical signs. Aphasia is not a disease but rather one of the consequences of a brain injury. Symptoms and recovery vary from one person to another according to the type of aphasia and the degree of brain damage.

Symptoms of aphasia

Aphasia is characterized by several easy-to-spot symptoms:

- Difficulty finding words and making full sentences
- Difficulty articulating and combining sounds
- Difficulty understanding, reading and writing.

Note

Sometimes the person is also paralysed on the right side. We describe such a person as hemiplegic.

To learn more, contact the
Groupe Relève pour Personnes Aphasiques des Laurentides
(Laurentian aphasics relief group)
www.grpa.ca *(site is French only).*

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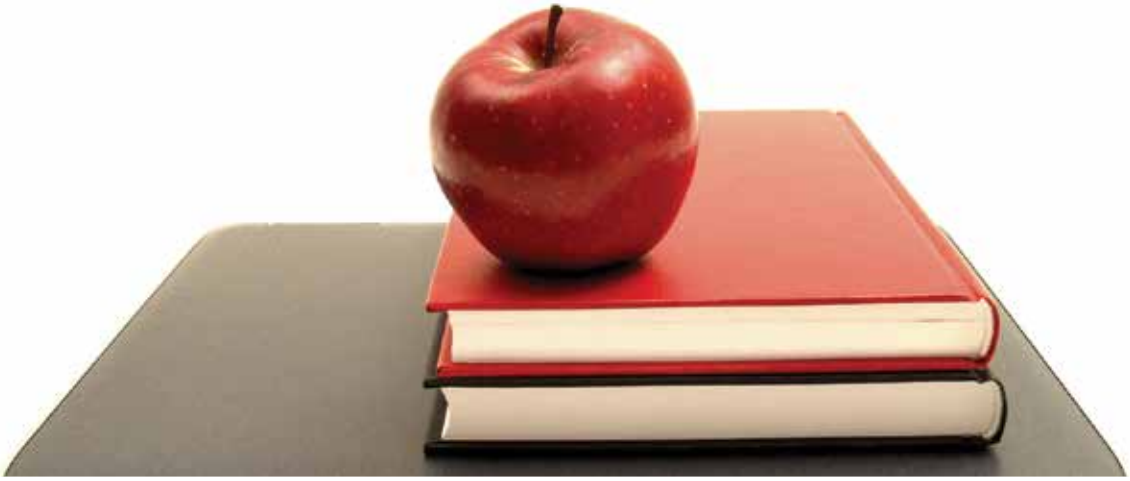
Role of Various Health Practitioners in Homecare Support



Along your path as a caregiver, you will experience various stages, some of them very difficult, as the state of health of your loved one deteriorates. Everything underscores the scale of the task the caregiver faces… Happily, you are not alone: a seasoned group of workers, working across a variety of disciplines, is available to help facilitate your progress. Let's take a look at who they are and the roles they play.

Well-educated specialists

The whole group of specialists who work alongside you, based on the needs and stage of the illness, are professionals recognized by the health network.

The specific interventions of each one

In addition to describing their roles, we will also focus on each professional's particular interventions and how they can respond to your own very specific needs.

"We make a living by what we get,
but we make a life by what we give."

—Winston Churchill

Health and Social Services Assistant

In collaboration with a multidisciplinary team, the health and social services assistant works with patients and their families in their own home with the goal of maintaining or developing optimal functioning in face of problematic situations. This assistant helps prevent family rupture or burnout and facilitates the keeping at home of the elderly person in terminal condition or with mental illness, cognitive impairment, chronic illness, disabilities, when convalescing or with family problems.

Specialized Educator

This professional intervenes with a person or with groups of people of every age who are experiencing or who may experience various adjustment difficulties. The specialized educator evaluates and supports the patient in daily life situations, including educational and helping relationships and intervention techniques. The educator's role consists of observing and evaluating the needs, abilities and lifestyle as well as behaviours of the person in care. They can also proceed to screening, to detection as well as to identification of undiagnosed problems. They must also evaluate the risk of suicide and the dangerousness of a person in a crisis situation.

Occupational Therapist

The occupational therapist in Homecare Support evaluates and intervenes with people of all ages who are losing autonomy, who have physical, cognitive or psychological disabilities. The therapist supports them and provides the tools to be able to preserve their abilities, to compensate for their disabilities, to adapt their environment with the aim of reducing situations that handicap them, thus optimizing independence.

Homecare Case Managers

The mandate of the case manager is to intervene with people who present a major and complex loss of autonomy in physical and cognitive functions, while having needs in several facets of their lives. This professional ensures the coordination of services. The case manager is the "conductor" of the patient's intervention plan, overseeing the working together of all the partners involved in the file and coordinating services in order to respond to the specific needs of the elderly person.

Nurse

The nurse is the person who takes on the responsibility for all the nursing care as a function of the health needs of the patients in their charge. As such, the nurse plans, provides and evaluates the nursing care and collaborates in the administration of preventive, diagnostic, therapeutic and curative care. In addition, the nurse participates in teaching patients and their caregivers to empower themselves.

The nurse responds to the need for nursing care according to a medical prescription. Care is offered in the home for the patient unable to go out, while guiding the patient to take responsibility for their own care and living conditions. The nursing team is made up of nurses and practical nurses. They work together with the patient to encourage a return to independence or, at a minimum, the stability that will allow them to continue remaining at home.

Respiratory Therapist

The CLSC respiratory therapist provides follow-up care, tests and instruction to patients who suffer from chronic obstructive pulmonary disease (COPD). This intervener follows the evolution of the disease, and helps the patient to remain as independent as possible at home, to improve their quality of life and to lower or avoid the need for hospitalization.

Doctor

The doctor on the Homecare Services team takes charge of all the medical needs in the home of the patient with diminished autonomy (disability, dementia, great age, chronic disease, terminal-phase cancer).

Social Worker

Psychosocial intervention is designed to support and help an individual, a couple, a family or a group experiencing social, psychological or relational problems, generally related to a loss of autonomy. The intervention takes into account the person's environment and encourages interactions that can contribute to resolving problems and improving the state of equilibrium, in the spirit of the person's taking responsibility and reclaiming personal power.

Nutritionist

This field of expertise consists of evaluating the nutritional state of a person. The nutritionist creates a nutritional treatment plan based around meals that fulfill the person's needs in order to maintain or re-establish good health, and ensures that it is followed. Within the Homecare Support system, they intervene primarily with people having reduced mobility, taking into account the resources available in the home and the involvement of the caregivers.

Nutritionists also work in private residences, in intermediate resources and in long-term care facilities. They work alongside others from the Homecare Services group, with hospital nutritionists, family physicians and other concerned health professionals.

Physiotherapists / Physical Rehabilitation Therapists

Specialists in neuro-musculo-skeletal and cardiovascular evaluation, physiotherapists can act as screening agents, not only in their own particular fields but also regarding biopsychosocial factors. Homecare practice also includes the evaluation of the physical characteristics of the home and the loan of technical aid devices. Physical rehabilitation therapists provide physiotherapy treatments following the evaluation done by the physiotherapists.

Home Respite Attendant (self-employed worker, employee, volunteer, health and social services assistant)

The home respite attendant (HRA), whether a self-employed worker, an employee, a volunteer, or a health and social services assistant, generally fulfills some or all of the following functions:

- Ensures a presence and provides supervision to people requiring it;
- Offers various stimulating activities to the person being cared for, according to their abilities, needs and interests. The HRA can also, when possible, accompany them when going out;
- Carries out light housekeeping tasks as well as light meal preparation, in collaboration with the person being helped.

Generally, home respite attendants have been trained in cardiopulmonary resuscitation (CPR), Principles for Safe Moving and Handling (PSMH) and the "prosthesis for care" approach. To learn more about the different types of respite, consult Section 3, Fact Sheet 16.

Daily Life Support Assistant

Daily life support assistants work primarily in DHSEBs or domestic help cooperatives. These offer domestic help services that complement those provided by the CLSCs and other groups. According the Quebec's Code National des Professions, they fill some or all of the following functions: sweeping, wiping, cleaning, waxing and polishing wood floors, dusting furniture and vacuuming , making beds, changing sheets, disinfecting and polishing household appliances as well as kitchen and bathroom fixtures, collecting and emptying garbage bins, preparing meals not requiring special diets, and running errands.

Reference: Taken from the document Collaborer pour mieux aider – La contribution des gestionnaires de cas CLSC-soutien à domicile (Collaborate to help better – the contribution of case managers from the CLSC-homecare support) prepared by the CSSS de St-Jérôme, Winter 2012.

Psychosocial Worker / Family Counsellor in a Community Group Context

The psychosocial worker and the family counsellor for caregivers work in similar ways. Here's an overview. They:

- provide psychosocial help to families and loved ones of people with chronic illnesses, disabilities, diminished autonomy or victims of accidents.
- prevent and spot signs of distress and exhaustion.
- inform the caregiver and direct them to available resources related to an evaluation of the needs and problems noted.
- participate in the coordination of information between the various people involved.
- as required, help people to manage conflict and improve communication, to find concrete solutions in order to improve the relationship dynamics.

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Among the many experiences that await you as a caregiver you will sometimes experience moments of great joy, but also periods of great frustration. Despite the very normal emotionalism you feel, you might come to the conclusion that the services being provided are sometimes not up to scratch. What to do in such a case? Who can you turn to in order to keep the situation from happening again?

The Users' and Residents' Committee

Protector of your rights, the Users' and Residents' Committee represents your first recourse if you feel that there is a problem. We will look at this committee and its role.

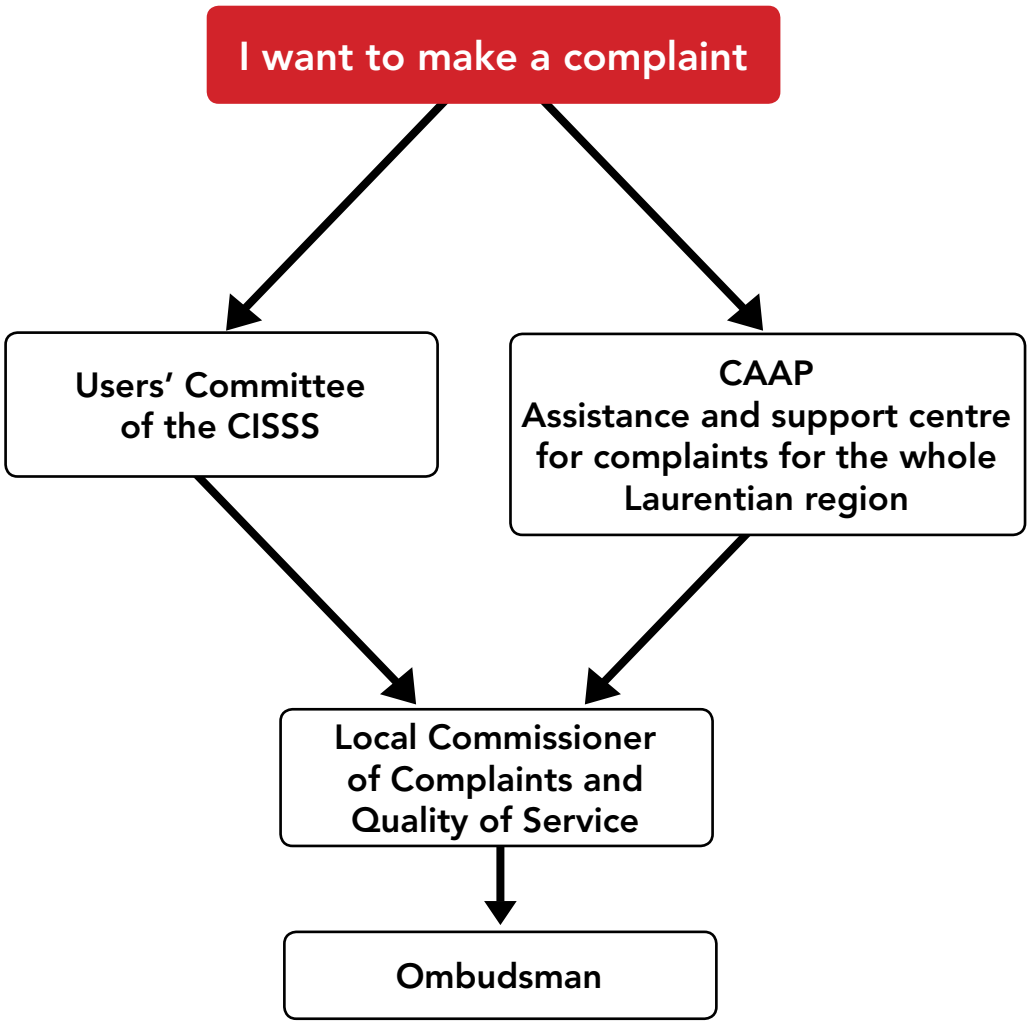
Your rights

We're not making this up, the Act Respecting Health Services and Social Services provides for the full range of your rights! What are they?

How to lodge a complaint: the CAAP

If your rights have been affected, that is the time to lodge a complaint. The CAAP, a community resource that provides help and support when making complaints, is an independent organization whose mission is to help and guide you.

Lodging a complaint greatly helps in improving the quality of care for everyone.


I want to make a complaint
Users' Committee of the CISSS
CAAP
Assistance and support centre for complaints for the whole Laurentian region
Local Commissioner of Complaints and Quality of Service
Ombudsman

The Users' and Residents' Committee

As a user of the health and social services network, you have rights and obligations. The Users' and Residents' Committee of your institution is there to protect these rights.

When you receive health care or psychosocial services and you encounter a problem or a lack of understanding, or when you have the impression that your rights have been affected, you can call on the Users' Committee.

Role of the Users' Committee

- Informs you about your rights and obligations.
- Defends your individual rights and interests as well as your collective rights and interests, at your request, within the institution or with any other competent authority where you have received care or services.
- Supports and assists you, upon your request, in all the steps that you want to undertake, whether facing those you have worked with or others, including if you want to lodge a complaint.
- Promotes improvements in the quality of services and the living conditions of users and evaluates your satisfaction regarding the services received in the institution.
- Ensures that your dignity is respected and that your rights and freedoms are recognized.
- Ensures the proper functioning of the Residents' Committees (in care facilities) and sees to it that they expend the necessary resources in carrying out their functions.

Your rights under the Act Respecting Health Services and Social Services

1. The right to information (Article 4); 2 parts
2. The right to services (Articles 5, 13 and 100)
3. The right to choose the professional or the institution to receive services from (Articles 6 and 13)
4. The right to receive the care required by your condition (Article 7)
5. The right to consent to or to refuse care (Articles 8 and 10)
6. The right to participate in decisions (Article 10)
7. The right to be accompanied, to be assisted and to be represented (Articles 11 and 12)
8. The right to accommodation (Article 14)
9. The right to receive services in English (Article 15)
10. The right to access to your personal records (Articles 17 to 28)
11. The right to the privacy of your personal records (Article 19)
12. The right to lodge a complaint (Articles 34, 44, 53, 60 and 73)

What to do in case the services received are unsatisfactory

First, identify the problem and try to discuss it with the people involved, whether it is about care or services. If you are not satisfied with the results of the discussion, you have the right to lodge a complaint.

How to lodge a complaint

To prepare a complaint, the user can be assisted and accompanied, if desired:

- by the Users' Committee of the institution;
- by the Local Commissioner of Complaints and Quality of Service;
- by the help and support centre for complaints (CAAP).
    - The CAAP is a community organization that provides assistance and support to people who wish to lodge a complaint when they judge that the services they received, or that they should have received, were unsatisfactory.

Who can lodge a complaint?

Any user of the health and social services network, the representative of a user, the heir or legal representative of a deceased user.

Who can be designated as the representative of a user?

Designated according to circumstances and subject to the priorities provided for in the Civil Code, the representative acts instead of and in place of the user, substituting for the latter and respecting their wishes. The following people can act:

1. The holder of parental authority for a user who is a minor, or the tutor of this user.
2. The guardian, the trustee, the spouse or a close relative of a user of full age under legal incapacity.
3. The person authorized by a mandate given before the incapacity by the user of full age under legal incapacity.
4. The person proving a special interest in the user of full age under legal incapacity.

To reach the Users' Committee, contact the health and social services centre in your region or consult the website: www.rpcu.qc.ca/en/index.aspx

Are you in a situation that must be corrected quickly?
Call the Users' Committee, which has the power to intervene directly at the appropriate administrative level, bringing about rapid change in case of a troublesome situation.

Section 6

End-of-Life Support

Fact Sheet

35 Palliative Care

With the goal of easing suffering, improving the quality of life and providing support near the end of life, palliative care is optimally provided by an interdisciplinary team of professionals possessing knowledge and competencies related to all aspects of the care process in their own fields of practice.

What is palliative care for?

Palliative care plays an essential role and is provided when the end is near.

Where is palliative care provided?

To receive palliative care, do you have to be in a hospital, a seniors' residence, with a specialized organization or at home?

"I will only live this life once.
Therefore let me do good, be good, today."

—Mohandas Gandhi

What is palliative care?

Aimed at patients and their caregivers, the goal of palliative care is to help them to:

- deal with the physical, psychological, social, spiritual and practical problems of the illness, as well as with the associated expectations, needs, hopes and fears.
- prepare to deal with the end-of-life stages, as defined by the patient, and to face the step that is death.
- overcome the loss and sorrow during the illness and the mourning period.

The palliative care team guides and supports the people involved right from the diagnosis to the end of life.

Where is palliative care provided?

Once it becomes possible and the family desires it, the person who needs palliative care can receive it as easily in hospital, in a long-term care facility, at home or in a palliative care hospice.

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At the Time of Death

Eventually, the inevitable happens. Even if you have tried to be well prepared, the death of a loved one always has major consequences, especially on an emotional level. It is good to know that, wherever the death takes place, the staff of the health network is there to support the survivors through this new stage.

When the death occurs in the hospital…

What happens then? Who takes charge of the situation? Count on the personnel of the health care network…

When the death occurs at home…

Even at home, the health care network personnel is right there beside you to help manage the situation.

"The most beautiful tombstone is in people's memory."

—André Malraux

When the death occurs...

In the hospital

The health services network personnel will evaluate the needs of the people surrounding the person who has died. However, when you lose a loved one, you must not hesitate to request psychosocial support. The health care network team is able to guide you through this period.

At home

When the person in the end-of-life stage decides to live out their last days at home, the homecare team of the CISSS supports the family. When the person dies, the family doctor or the duty doctor will go to the home to certify the death. The funeral home can then pick up the body of the person who has died.

When death occurs in a palliative care hospice

When a person dies in a palliative care hospice, the care team (doctors, nurses, volunteers, psychologists) support the family. It is the duty doctor's responsibility to certify the death. You can remain with the body for several hours before the funeral home comes to pick it up. Several months after the death, telephone follow-up is done to ensure that the mourning period is progressing normally. If not, family members who need help will be offered the appropriate services.

In a long-term care facility

When a death occurs in a long-term care facility, the personnel is able to help you, either a nursing assistant, a social worker or a member of the team with whom you have developed close ties. A helpful booklet entitled What to Do in the Event of Death is available from Services Québec along with a list of resources or readings on mourning. Some long-term care facilities also include palliative care beds.

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37 After the Death

Once the sad event has occurred, what happens? Even though the personnel of the health services network are always there to provide you with their support, a new player will now provide you with the guidance you need. This is the funeral home, whose specialists have the required qualifications to accompany you through all the steps that follow the death of a loved one.

The death benefit

Did you know that the Quebec government provides a death benefit payment? It can also provide other useful services, such as cancellation of the medicare card.

Funeral prearrangements

This is talked about a lot, often ironically. But what are funeral prearrangements like and what is the advantage of them?

"Don't cry for the person you have lost.
On the contrary, rejoice that you knew them."

—Jean-Louis Trintignant

The death benefit

During a meeting at the funeral home or funeral cooperative, the counsellors will give you forms to fill out in order to receive the death benefit payments provided by the provincial government. The funeral home or cooperative will also manage other services, such as the cancellation of the medicare card and the issuing of the death certificate. The establishment will also provide you with a list of the places that you need to communicate with following the death of your loved one.

Funeral prearrangements

As death approaches, and even before, it is possible to plan what follows death by prearranging the funeral. This contract contains three sections: the services, the products and the expenses involved in the future funeral. Once those sections are filled in, the amount of money due to the funeral home of your choice is placed in trust until the death occurs. In case of cancellation of the contract, a 10% administrative fee will be deducted.

Valuable advantages

It is obviously not necessary to make prearrangements. However, taking into account the state in which we find ourselves at the time of a death, it can be wise to choose this option. Here are some of the principal advantages of funeral prearrangements:

1. Clears many worries at the time of death
2. Allows people to share their wishes for the end of their lives
3. Ensures agreement among family members

Did you know?

When a person dies without a prearranged funeral, the procedure for the choice of services, the products and expenses will be determined by the survivors at the time of the death.

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38 Mourning

Mourning represents a sometimes difficult and traumatizing step, which can even make life hard to bear. The months that follow the death of a loved one risk seeming particularly difficult to you as the people who made up your support network go back to their normal lives, leaving you to define your own new "normal." How can your experience of mourning be improved? When will you regain your sense of peace?

The stages of mourning

In all cases, the grieving person will go through several stages. Although people will experience each of these stages for different lengths of time, they are all essential for regaining a sense of peace.

Know how to ask for help

With all the changes and upsets associated with death, with the loss of a loved one, suffering is normal. In this situation, why not ask for help?

The mourning curve

A graphic illustrating the stages experienced by a person in mourning. A way to help visualize your feelings…

"Someone dies, and it is as though movement stops.
But, what if this is the departure on a new voyage…"

—Benoît Marchon

The stages of mourning

Mourning the loss of a loved one is accompanied by social and cultural rituals. Everyone is confronted by strong emotions whose intensity and frequency vary. It is normal to feel such emotions, that's part of the process. The mourning period is the time to deal with the emotional reactions a person may feel during each of the four stages:

- Accepting the reality of the loss
- Experiencing pain and affective suffering
- Learning to live without the loved one
- Accepting your new life

A question of time…

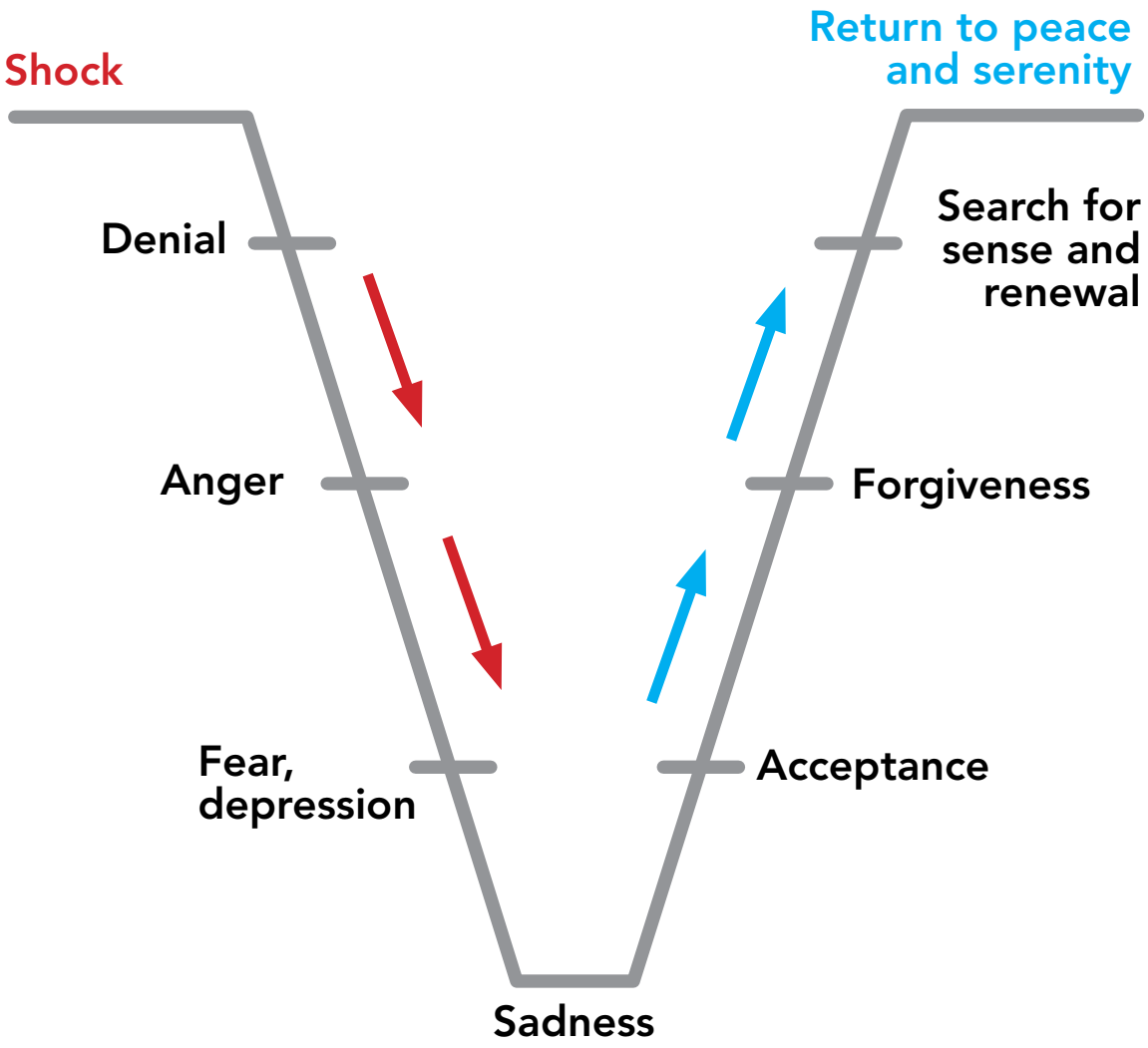
It isn't easy to predict how long a period of mourning will last. The symptoms of grief will lessen over time, but certain triggers and significant events, such as vacations and holidays, risk reviving deep feelings of grief. There is only one solution that will help you feel better: patience and the passage of time…

Know how to ask for help

As time passes, when it is time to return to work or to re-establish your habits and your daily activities, you may be faced with questions of a practical nature. On the emotional level, you will have the more difficult adjustment to the changes that affect your own life. During this period, don't hesitate to ask for professional or spiritual help, or talk to members of your family or circle. You have to talk about your emotions, and members of the network can play a valuable role. Give yourself the right to experience each step at your own pace. Don't hesitate to join a grief counselling group. They are offered by some community groups or through your CLSC.

The mourning curve

A quick look at the emotions experienced during the mourning process



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Life Goes On... Finding Your New Identity 39

Throughout life, we go through turning points, often very important ones that cause many changes in our values and identities. Becoming a caregiver is one of those times. Each of these periods brings with it a great gift: greater self-knowledge. If you stop to think about it, the caregiver's role can teach you a lot about yourself.

The importance of taking stock of your life

After so many upheavals, it makes sense to examine your recent life as a caregiver, and to reflect on the consequences of this life choice.

The steps to take

Rebuilding your life is no picnic. But by proceeding one step at a time it is possible to find your bearings and to begin a new era of happiness.

Readings and references

Life after mourning is a subject that has been written about extensively. Here are a few recommended readings for the next stage of your life.

"Look around at how people want to get more out of life than they put in.
A man of value will give more than he receives."

—Albert Einstein

The importance of taking stock of your life

Taking care of someone who is losing autonomy turns your habits upside-down, without changing your deep personal identity. Take stock by asking yourself the following questions: How have I experienced the changes in my life? Is adapting easy for me? What behaviours have I developed to deal with these changes? What are my points of resistance, my fears, my insecurities? Do I have moral support around me?

A major life change, such as a departure or a death, creates a period of discomfort tied to the various emotions you experience. The more prepared you are for such a change, the easier it will be to face it, depending on the time and space that your role as caregiver took up.

The steps to take

As a result of taking stock, certain steps leading towards a redefinition of your life plan will appear to you. Many more steps remain to be taken to arrive at a final result.

1. What is your plan? (Define it in detail, with whom, when, where?)
2. What is important to you in this new phase of your life?
3. How will you know if you have attained your goals in this new life?
4. What are the advantages and disadvantages for you and your entourage of setting this plan in motion?
5. What resources do you need to experience this new stage of your life in a satisfying way? (personal, material, financial, family and friends)
6. What are the steps to be taken?
7. What is the first step? And the next one?

Readings and references

You will find a list of readings and references about mourning in Fact Sheet 43.

KÜBLER-ROSS, ELISABETH. To Live Until We Say Goodbye. Touchstone, 1997.

MONBOURQUETTE, JEAN. Aimer, perdre et grandir (in French only). Novalis, 2007.

Government organizations

What to Do in the Event of Death – Quebec government **www4.gouv.qc.ca/EN/Portail/Citoyens/Evenements/deces/Pages/accueil.aspx**

Quebec Consumer Protection Office **www.opc.gouv.qc.ca/en/home/**

Quebec Register of Personal and Moveable Real Rights **www.rdprm.gouv.qc.ca/en/pages/english.html**

Quebec Coroner's Office **www.coroner.gouv.qc.ca** (in French only)

Quebec Public Curator **www.curateur.gouv.qc.ca/cura/en/index.html**

Registrar of Civil Status **www.etatcivil.gouv.qc.ca/en/default.html**

Revenu Québec **www.revenuquebec.ca/en/**

Health insurance board **www.ramq.gouv.qc.ca/en/Pages/home.aspx**

Canada Revenue Agency **www.cra-arc.gc.ca/menu-eng.html**

«Laurentian integrated health and social services centre CISSS **www.santelaurentides.qc.ca/en/home.html**

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Closing Remarks

This Guide was produced as the result of the experiences of many caregivers who helped us to identify the needs of those people who so generously accompany a loved one in the final steps of their end-of-life journey. In putting it together, we wanted to help you in your search for information so that you can find the answers and the resources you need without wasting time, at a time when every minute counts.

We hope that this information has been useful to you and it will continue to be so. We aimed to provide the most information possible in a succinct manner, keeping in mind both the person being cared for and the caregiver.

Here we are at the end of the Guide, and also possibly at the end of your journey as a caregiver. It is up to you now to determine what the next stage in your life will be, enriched by all this experience and your valuable memories. Let us end this journey with the thoughts of Robert Louis Stevenson: "Don't judge each day by the harvest you reap but by the seeds that you plant."

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List of Abbreviations

List of Abbreviations

CAAP:	Centre d'Assistance et d'Accompagnement aux Plaintes, assistance and support centre for complaints
CAB:	Centre d'Action Bénévole, volunteer bureau
CHSLD:	Centre d'Hébergement et de Soins de Longue Durée, long-term care facility
CISSSL	Centre Intégré de Santé et de Services Sociaux, integrated health and social services centre
CLSC:	Centre Local de Services Communautaires, local community services centre
COPD:	Chronic Obstructive Pulmonary Disease
CPR:	Cardiopulmonary Resuscitation
CRA:	Canada Revenue Agency
CISSS:	Centre de Santé et de Services Sociaux, health and social services centre
CSST:	Commission de la Santé et de la Sécurité du Travail du Québec, Quebec workers' health and safety commission
DHSEB:	Domestic Help Social Economy Business
HRA:	Home Respite Attendant
IR:	Intermediate Resource
LRH:	Low-Rental Housing – habitations à loyer modique (HLM)
MSSS:	Ministère de la Santé et des Services Sociaux, Quebec Ministry of Health and Social Services
NPO:	Non-Profit Organization – Organisme à But Non-Lucratif (OBNL)
PSMH:	Principles for Safe Moving and Handling
RAMQ:	Régie de l'Assurance Maladie du Québec, Quebec health insurance board
RBQ:	Régie du Bâtiment du Québec, Quebec agency that oversees building contractors
SAAQ:	Société de l'assurance automobile du Québec, Quebec automobile insurance corporation
SHQ:	Société d'Habitation du Québec, Quebec's housing authority
VaD:	Vascular Dementia

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Québec

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Fact Sheet 43

Useful Links

Fact Sheet 1
www.helpguide.org/articles/caregiving/caregiving-support-and-help.htm

Fact Sheet 2
www.helpguide.org/articles/caregiving/caregiving-support-and-help.htm#support

Fact Sheet 3
www.nextstepincare.org/next_step_in_care_guides/216/Becoming_a_Caregiver

Fact Sheet 4
www.morethanmedication.ca/en/article/index/healpful_network

Fact Sheet 5
www.lappui.org/laurentides

Fact Sheet 6
www.morethanmedication.ca/en/article/index/Caregiver_Stress
www.chairedesjardins.umontreal.ca/documents/DepliantGestionduStress-webE.pdf

Fact Sheet 7
www.chairedesjardins.umontreal.ca/documents/takingcareofmyself_en.pdf
www.phac-aspc.gc.ca/publicat/oes-bsu-02/caregvr-eng.php
www.alzheimer.ca/~/media/Files/national/Core-lit-brochures/reducing_caregiver_stress_e.pdf

Fact Sheet 8
www.alz.org/care/alzheimers-dementia-healthy-caregiver.asp

Fact Sheet 9
www.csep.ca/CMFiles/Guidelines/CSEP_Guidelines_Handbook.pdf
www.csep.ca/CMFiles/Guidelines/CSEP_Guidelines_Blank-Log_18-65plus_en.pdf

Fact Sheet 10
www.healthycanadians.gc.ca/eating-nutrition/food-guide-aliment/index-eng.php

Fact Sheet 11
www.seniorlivingmag.com/articles/reducing-caregiver-isolation

Fact Sheet 12
www.statcan.gc.ca/pub/75-001-x/10904/7033-eng.htm

Fact Sheet 13
www.ordrepsy.qc.ca/en/index.sn
www.alz.org/care/alzheimers-dementia-caregiver-depression.asp

Fact Sheet 14
This Guide is a project originally initiated by the group l'Ant'aidant

Fact Sheet 15
CISSS Antoine-Labelle : www.cisssal.org
CISSS Argenteuil : www.cisssargenteuil.qc.ca
CISSS des Pays-d'en-Haut : www.cissspdh.net
CISSS de Saint-Jérôme : www.cdsj.org
CISSS des Sommet : www.cisss-sommets.com
CISSS Thérèse-de-Blainville : www.cisstheresedeblainville.qc.ca
CISSS du Lac-des-Deux-Montagnes : www.moncsss.com

Fact Sheet 16
www.lappui.org/laurentides/repertoire-des-services/repit/s
www.healthcarecan.ca/wp-content/uploads/2012/11/Respite_Care_in_Canada_EN_web.pdf

Fact Sheet 17
www.lappui.org/laurentides/repertoire-des-services

Fact Sheet 18
www.nextstepincare.org/uploads/File/Guides/Provider/Provider_Dementia.pdf

Fact Sheet 19
www.educaloi.qc.ca/en/capsules/medical-records-who-can-have-access
www.nextstepincare.org/next_step_in_care_guides/303/Doctor_Visits

Fact Sheet 20
www.habitation.gouv.qc.ca/english.html

Fact Sheet 21
www.phac-aspc.gc.ca/seniors-aines/ips-pba-eng.php

Fact Sheet 22
www.saaq.gouv.qc.ca/en/miscellany/parking_permit/index.php

Fact Sheet 23
www.mtq.gouv.qc.ca

Fact Sheet 24
www.mv1canada.com
www.saaq.gouv.qc.ca/en/road_safety/vehicles/wheelchair_lift/index.php

Fact Sheet 25
www.barreau.qc.ca/en/barreau/bottin/
www3.publicationsduquebec.gouv.qc.ca/loisreglements/loisrefondues.en.html
www.curateur.gouv.qc.ca/cura/publications/mandatE.pdf

Fact Sheet 26
www.cra-arc.gc.ca
http://www.seniors.gc.ca/eng/sb/caregivers/qc/financial.shtml

Fact Sheet 27
www.servicecanada.gc.ca/eng/lifeevents/caregiver.shtml

Fact Sheet 28
www4.gouv.qc.ca/EN/Portail/Citoyens/Evenements/aines/Pages/placement-adulte-centre-hebergement.aspx
www.santemontreal.qc.ca/en/where-to-go/residential-resources/

Fact Sheet 29
www.ramq.gouv.qc.ca/en/Pages/home.aspx
www.ramq.gouv.qc.ca/en/citizens/aid-programs/Pages/accomodation-public-facility.aspx
www.ramq.gouv.qc.ca/en/citizens/aid-programs/Pages/accomodation-in-intermediate-resource.aspx

Fact Sheet 30
www.fcns-caregiving.org/wp-content/uploads/2012/12/Involuntary-Separation.pdf

Fact Sheet 31
www.alzheimer.ca/en/Living-with-dementia/Caring-for-someone/Long-term-care/Moving-to-long-term-care

Fact Sheet 32
www.parkinsonquebec.ca
www.lung.ca
www.diabete.qc.ca/en
www.alzheimer.ca/en
www.aphasie.ca/1/en/home/aqpa-homepage
www.heartandstroke.qc.ca

Fact Sheet 33
www.caring-for-aging-parents.com/elderly-health-care.html

Fact Sheet 34
www.santelaurentides.qc.ca/en/health_care_and_services/service_quality/service_quality_and_complaints.html
www.rpcu.qc.ca/en/your_rightsLSSSS.aspx

Fact Sheet 35
www.hc-sc.gc.ca/hcs-sss/palliat/index-eng.php

Fact Sheet 36
www.servicecanada.gc.ca/eng/lifeevents/loss.shtml

Fact Sheet 37
www.rrq.gouv.qc.ca/SiteCollectionDocuments/www.rrq.gouv.qc/Anglais/publications/regime_rentes/deces/deces_en.pdf

Fact Sheet 38
www.cmha.ca/mental_health/grieving/#.VP86bPnF9v8

Fact Sheet 39
See links in text

Other sites:
www.seniors.gc.ca/eng/sb/caregivers/qc/index.shtml
www.mssociety.ca
www.cancer.ca