

TAKING CARE OF YOURSELF... WHILE TAKING CARE OF YOUR LOVED ONE

Recognizing yourself as a caregiver



Companion Guide for Caregivers

Agence de la santé
et des services sociaux
de Laval

Québec 



Companion Guide for Caregivers



Association Lavalloise des Personnes Aidantes

Acknowledgements

We warmly thank all the groups that produced a similar guide before ours. The adaptation chain is a long one and the consulted documents were our source of information and inspiration.

The information and awareness-raising book, *L'Entourage*, produced by the *Regroupement des aidantes et aidants naturels de Montréal* and the Guides by the *Regroupement de la région de Chaudières-Appalaches* and the *Regroupement de la région de la Mauricie* should be mentioned.

Caregivers' living conditions continue to improve, thanks to their involvement within the various groups. The work of the researchers, health professionals, and people who take this cause to heart, has increased their social and political recognition.

Much awareness-raising still remains to be done so that caregivers can receive better support throughout this journey, which too often still leads them to burnout, impoverishment and solitude.

We want to thank all those individuals who are participating in this way to the well-being of caregivers and particularly those individuals who have contributed to the production of this guide and to its funding.

Working committee

Johanne **LÉTOURNEAU**, Social worker
CSSS de Laval

Éliette **PARENT**, Caregiver
Association Lavalloise des Personnes Aidantes (ALPA)

Odette **PICARD**, Assistant to management
Association Lavalloise des Personnes Aidantes (ALPA)

Normand **PLANTE**, Community organizer
CSSS de Laval

Richard **ROUSSEAU**, Caregiver
Association Lavalloise des Personnes Aidantes (ALPA)

Lily **TREMBLAY**, Director
Association Lavalloise des Personnes Aidantes (ALPA)

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Preliminary note

In this document, we use the term "caregiver" to designate a person who regularly takes care of a compromised loved one without compensation. This term is the one chosen by the Association Lavalloise des Personnes Aidantes since its inception.

"Proche-aidant" (informal caregiver) is the term used by the ministère de la Santé et des Services sociaux du Québec in its home support policy called *Chez soi: le premier choix* (MSSS, 2003). Historically, "natural caregiver" has been used in numerous studies and by various organizations. Most people recognize themselves in these terms because they are widely used in the media. Regardless of the name, we are always talking about the same reality.

Even if she carries out her tasks for free, a caregiver is not a volunteer. This name is generally reserved for a person who provides help, without obligation or compensation, for a member of the community who is not a close family member.

This guide is intended for all those individuals who take care of a loved one, without distinction or discrimination. We know that the great majority of caregivers are women, but we also know that men will increasingly have to take on this role. Every one of us is likely to be faced with this reality sooner or later.

Caregivers are also parents whose task goes far beyond the usual role, namely those who must take care of a sick or disabled child, or one with a major disability. In this case, recognizing yourself as a caregiver and parent is a real challenge.

The term "person being helped" is used to lighten the text. It refers to the person who receives the help from the caregiver without consideration of his/her gender, age or disability.

Introduction

Since its inception in 2002, the Association Lavalloise des Personnes Aidantes (ALPA) took on the mission to improve caregivers' living conditions for personal, family and social well-being. ALPA works to represent caregivers with different levels of governments and participates on several issue tables in Laval.

We also offer opportunities for dialogue and support, individually or in groups, lectures and thematic discussions, and social and cultural activities. Just recently, a home respite service was established, in order to maintain a balance between giving your time and giving yourself time. We hope that this guide will be an additional tool to help you achieve well-being.

The need for caregivers to take care of themselves no longer has to be demonstrated. By consulting this guide, you will know that you are not the only ones living with this commitment, and that numerous resources have been set up to help you take care of yourself while taking care of a loved one.

You are invited to reflect on the different aspects of a caregiver's reality and role. Your situation is unique, and how you take care of yourself will be just as unique.

This guide is the result of several years of experience of caregivers, health professionals and researchers, who have made the needs and recognition of caregivers their primary concern. We are offering you solution scenarios and means to increase your decision-making power and your ability to act.

This guide also contains a list of the organizations and resources that are available to you on Laval territory, but also for Québec residents.

1

Recognizing yourself as a caregiver



"Being there for someone means putting yourself neither in front nor behind, nor in their place. It means being alongside them." (free translation)
(L'amour partagé, Joseph Templier)

1.1

Picture of a caregiver's situation

- Caregivers take on from 70 to 90% of the responsibilities for the person being helped. CSSSs and community organizations share the rest;
- More than 80% of caregivers are women; this is why several studies talk about caregivers as female;
- They are the spouse (close to 40%), daughter (close to 44%), mother, sister, girlfriend or neighbour;
- Their average age is 46 years;
- Numerous caregivers are in the labour force;
- They take care of disabled people of all ages. For example: an autistic, disabled or intellectually disabled child; an adult with a physical impairment, a chronic disease or losing his autonomy, etc;
- They increasingly care for people over 65 years of age;
- Their risk of death increases by 60% when they are themselves elderly and in poor health;
- They provide 8 to 40 hours of care per week, and the tendency is that the older you become, the greater this number of hours;
- Pressure on caregivers is growing because families are becoming increasingly smaller and home care does not meet needs.

1.2

Being a caregiver

Definition

According to the Ministère de la Santé et des Services sociaux, "Any person in the entourage who provides significant, continuous or occasional support, as a non-professional, to a person with a disability, is considered an informal caregiver. It can be a family member or a friend." (free translation).

For ALPA, a caregiver takes care of a person losing his autonomy or with limited autonomy by offering him emotional support, by providing him with care, or by providing him with various services in order to improve his living conditions.

Are you one of these people ?

For example, do you...

- Provide hygiene care, help a person get dressed, shave, comb his hair, etc. ?
- Prepare his meals, help him grocery shop, go shopping, do his housekeeping ?
- Supervise his medication, accompany him during medical visits, and supervise his comings and goings?
- Visit a loved one in a residence or a foster family?
- Provide him with care under a nurse's supervision?

Being a caregiver involves numerous responsibilities, but also rewarding and enriching aspects, such as :

- Enjoying being of service and feeling useful;
- Developing a deeper relationship with the person being helped;
- Giving meaning to your life.

However, being a caregiver leads to life changes such as:

- Regularly changing your schedule according to the person being helped;
- Adapting to the change in the disease, old age;
- Feeling isolated because of what you are doing;
- Dealing with task overload;
- Having difficulty carrying out all your roles (parent, spouse, child, worker);
- Undergoing a change in role (e.g., you feel you are becoming the mother of your parent);
- Changing your life or retirement projects;
- Noticing that this commitment can have an impact on your financial situation.

If you see yourself in several of these activities or feelings, you are without a doubt a caregiver.

How does one become a caregiver ?

You don't become a caregiver overnight... The reality of taking care of a loved one losing his autonomy emerges gradually. The tasks and responsibilities for which you are not necessarily prepared increase over months, and sometimes years. Without being aware of it, the signs of stress and fatigue can increase and may exhaust you. Taking action then becomes more difficult.

You take care of a person losing his autonomy for different reasons. Of course, you come to the aid of your loved one because of love and affection. You always have a choice, even if this concept sometimes seems limited to you. However, some motivations are more subtle. You may for example seek recognition from the person being helped or from the family.

Taking responsibility for carrying out all the tasks as though you were the only person able to do them can be a heavy burden. You want the house to be impeccable, the person you are helping to always have clean beautiful clothes, his hair well combed, to be well shaven... Otherwise, you wonder what other people will say or think!

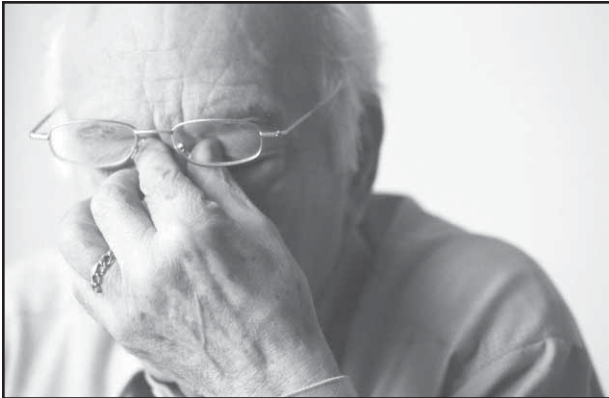
Feeling completely responsible for the person being helped while wanting to please others requires enormous energy. This does not allow you the right to make a mistake, to be tired or even the right to slow down from time to time. Wanting everything always to be perfect, that's great... but at what cost? The "I must," "I should," "I should therefore have" are part of a vocabulary to be eliminated because they encourage a feeling of guilt, an unnecessary and unrealistic obligation; most of the time, the person being helped asks only for a reassuring presence. It is very possible that your loved one can help in some simple tasks or still carry out activities that he liked, by adapting how he does them. In this way, you can benefit from wonderful times together.

We ask you to reflect seriously on your situation, without, however, neglecting or abandoning your role as caregiver. Ask yourself what is really important to you today: seeking perfection, receiving the approval of those around you, trying to do your best while maintaining a good quality of life, or meeting all the expectations of the person being helped?

Remind yourself that being a caregiver involves a choice, sometimes rewarding, sometimes exhausting. As a caregiver, you can make some choices to take care of yourself while taking care of the other person. It is always possible to find better support around you and to take advantage of the resources at your disposal.

2

How to avoid exhaustion



"To be able to provide real help to a loved one, taking care of yourself is vital."
(A health professional)

Recognizing signs of stress: avoiding exhaustion

When you are a caregiver, you expect hectic times. As long as these situations stimulate you and make you give the best of yourself, you have nothing to worry about. But if a stressful situation continues and you don't seek the help that you need, destructive stress can begin. You can recognize it from the following symptoms:

- General irritability, impulsiveness;
- Frequent desire to cry or to run away;
- Difficulty concentrating;
- Fatigue and loss of pleasure in life;
- Vague anxiety, fear, insomnia, nightmares;
- Loss of appetite or bulimia;
- Tendency to take medication or consume alcohol.

If you have several of these symptoms, it is time to take stock, meaning:

- Precisely assess what initiated this stress, when, where and how;
- Apologize for having been impatient or irritable, thus prompting your loved ones to be indulgent, generous;
- Understand that it is vital that you do enjoyable activities that are just for you: an activity that you like, such as singing, sewing, painting, a sport, or something else;
- Arrange opportunities and times FOR PLEASING YOURSELF through small frequent daily rewards that don't cost a lot of money: going to the movies, walking, reading a good book;
- Open yourself up to sharing your life experience with your family members, counsellors or support groups which, in turn, will encourage you to develop a positive confident attitude in your personal resources;
- Ask for help from family members, friends, a doctor, a social worker, the CLSC, an organization such as **ALPA - Association Lavalloise des Personnes Aidantes**.

Obstacles to asking for help

Do you sometimes say to yourself...

"Everything rests on my shoulders. I'm in good health. The other person's needs are more important than mine. Don't feel sorry for yourself. Don't let yourself go. I can't be heartless. I don't have any choice about getting involved."

If so, you are certainly feeling the most common feeling among caregivers:

Guilt!

Ah! **Guilt!** The little inner voice that tells you that you are wrong to think about yourself, even if you realize that you need help or free time to recharge your batteries!

Numerous caregivers believe that they are completely responsible for their loved one who is losing his autonomy, and take on all the care alone. As a result, they often become sick themselves. Of course, taking care of the other person is important, but taking care of yourself is just as important in order to respect your limitations. After all, if you don't take care of yourself, who will?

We need to pay attention to our feelings and our body. We need to be kind to ourselves. We need to always remember that taking time for ourselves is a necessary health promotion activity, and not self-indulgence. All kinds of experts will tell you: "Taking care of yourself" is necessary when you live a life of commitment. Whether this commitment is at work, in family life or as a volunteer, sooner or later you learn that you have to take care of yourself to be able to continue. Paradoxically, the more rewarding our commitments, the more likely they are to isolate us.

Many people think that caregivers don't ask for outside help because they don't know about the services that could help them. This statement is true, but is not the main reason. Unfortunately, **studies show that caregivers seek help if and only if they can't cope any longer.**

Main reasons for not asking for help

Most caregivers are women and they often take on alone all the care and support that their loved one requires because they feel obliged to do it (for example, children are working, or brothers and sisters don't live in the area). This may be your situation. Women, and mainly older ones, are not accustomed to asking for help, and even less to taking time for themselves!

"Our education, which taught us to give without keeping score, fooled us. We had to forget ourselves to please others. Learning to assert ourselves is not that easy."

A lot of people don't want help, and even less so from a stranger, "because personal business must remain private." The caregiver often wants to protect herself from judgements or from "gossip" about the person being helped. You may also think that your loved one will be too uncomfortable, that things will not be done as well as you do them, etc.

"When I accept help, I'm taking a step, I'm recognizing my limitations, I'm breaking the silence."

Messages from the people around you may influence you and even persuade you not to ask for help. Perhaps you have already heard comments such as:

"How can you say that you can't cope anymore after all that Mom has done for you?" "Dad is not that sick. You're exaggerating!" And these well-known "encouragements" that are far from encouraging! "Come on, you can do it. Don't let yourself go!" "We have confidence in you! You can do it..."

Finally, many caregivers don't want to ask for help because they believe that the services available are inadequate. The slowness in handling requests for services, the difficulty in obtaining access to care in emergencies or on weekends discourages them even before they start. On top of all this is the fear of the financial losses related to the help to be received, because the services are not always free and the impoverishment of caregivers is a reality.

Due to her loved one's loss of autonomy and the increasingly demanding care, the caregiver can see the different areas of her life shrinking (work, outings, neighbourhood, conjugal life, etc.). The person being helped is at the centre of her life and everything becomes organized around it. The caregiver then forgets her own needs. It is important to maintain your identity. If you don't allow yourself some distractions, you could end up with nothing to give to others, and also feel frustrated, bitter and sometimes even angry.

Among these reasons, you have recognized reasons that are similar to your own for not asking for help. Remember that if you continue to have these beliefs, you will continue to do everything alone. You could become exhausted over time. You have perhaps become accustomed to thinking these thoughts for many years. They are difficult roadblocks, but getting beyond them will enable you to change your situation in a positive way.

Talking about prevention

"When I felt that everything was falling on me and that it didn't stop... I no longer saw any solutions. I even considered... suicide."

Relief...

It is completely normal to want to avoid exhaustion. The stress that exhaustion can cause makes us react in different ways. Some exhausted caregivers try to relieve their suffering by drinking alcohol or taking medication. This can result in symptoms of depression and even ideas of suicide. These painful situations can lead to abuse, negligence and sometimes even violence in the relationship between the caregiver and the person being helped. Therefore, symptoms of exhaustion must not be trivialized because the consequences can be dramatic over the long term.

Or prevention?

Prevention means stopping to think about your situation as a caregiver and finding ways to avoid exhaustion. The ideal, of course, is to act when you start taking care of the person being helped, but it is never too late! Remember that each caregiver's situation is specific and unique. You therefore cannot generalize about the methods and means of obtaining the help and support that meet your needs. Each person can determine the solutions that are appropriate for her.

Right now, you may have the impression that you are no longer able to regain your energy. However, you can make changes to your life. You will need to take time for yourself, and other people can become involved in taking care of your loved one. These changes may seem difficult to you, but are necessary to allow you to "recharge your batteries" in order to continue in your role as caregiver, if this is your decision.

Autonomy is not measured by the number of tasks that you can carry out alone, but by the quality of life that you achieve with help.

Finding ways to feel better

Recognize your limitations

Despite all your good will and the resistance you may feel, accept that you cannot do everything alone. Consider the circumstances in which you will need help in order to provide the services that your loved one or you will need to stay in shape.

"Now that I am aware of my limitations, it is becoming easier to respect myself and to ask for help."

Recognize your successes!

You have qualities and strengths. Be proud of your small successes just like you are of your great victories... Congratulate yourself, it feels good!

Accept what you feel

Taking care of someone can produce many emotions every day, sometimes happy ones, sometimes painful ones. You may feel irritable, guilty, discouraged, misunderstood, ashamed, impatient, intolerant, etc. As a caregiver, you experience a complete range of emotions and questions that are neither good nor bad. Tell yourself, however, that they must be recognized and accepted. These emotions do not mean that you are a bad caregiver, but only that you are human and probably tired.

Share your emotions and break your isolation

Accept the fact that you are not the only one feeling pressure and allow yourself to talk about what is worrying you and what you are dealing with. Think of someone with whom you feel comfortable among the people around you. You can also confide in your doctor, a psychologist, a social worker, or participate in a support group at your CSSS, or even join a community organization whose mission is to take care of caregivers. These resources are there to support you and to answer your questions, in complete confidentiality. Consult the list of these different organizations that is included in the **information pocket**.

People who benefit from support from family and friends can deal with stress and resist disease better than those who try to do everything themselves. Sometimes, the reasons for stress build up without interruption. The best efforts don't change anything. We feel trapped, prisoners, immobilized. At this stage, making use of outside help is one way of dealing with the problems; it is a sign of strength and not of weakness. Breaking our isolation allows us to take a step back from our role as caregiver so that we can better identify our limitations.

Communicate better...

Good communication is the basis for all good relationships. The way the message is expressed is more important than the message itself. Communication is an active process, an exchange of symbols and signs. Considering the complexity of communication and the many possible obstacles, it is rather surprising that we are able to make ourselves understood!

It is impossible not to communicate. Every time that we are with another person, we send messages, spoken or unspoken. Listening is probably the most important communication skill that we can acquire. Empathy, the ability to put yourself in someone else's shoes, is an essential quality for improving our listening. The greatest gift that we can offer someone is to listen to them.

We should not underestimate the importance of touch in good communication with more vulnerable people. A hug or a gentle pat on the arm can do a lot to make a person feel worthwhile.

Humour can also be an effective communication tool when used correctly. Ridicule or sarcasm at the other person's expense should be avoided. Humour can "defuse" a situation, help us get out of an embarrassing situation, or lighten a routine task.

We need to realize that many variables consciously or unconsciously affect our ability to deliver a message, to receive a message, or to understand its meaning. Disease, exhaustion, and frustration are many factors that can impede good communication. Sometimes, we must simply accept the fact that truly effective communication is not always possible. This is the case with some diseases such as Alzheimer's. But we can adopt an attitude of respect and tolerance for the difficulties encountered.

Take care of your health

Don't forget to take care of your health. It is absolutely necessary in order to continue to fulfill your role as caregiver. Eat balanced meals and consult your doctor as needed. Find ways to move, relax, and get enough rest. To be able to do this, you have to keep some time for yourself. Stay in contact with what is important to maintain your identity. Resume activities or get back with people whom you like and who make you feel good...

Give yourself these small pleasures in life that help you "recharge" your batteries:

- Take a nap;
- Take care of your plants, garden;
- Do manual work: crafts, cook, knit, draw...;
- Walk;
- Get captivated by reading;
- Lose yourself in a piece of music;
- Practice a relaxation technique, do yoga.

Remember that the important thing is to reserve time for yourself every day, and to write yourself into your agenda. Devote this time to an activity of your choice that gives you pleasure.



2.5

Asking for help is learned

"But they see very well that I am exhausted... Why doesn't anyone help me?"

It is frustrating to note that often our family and our friends offer no help or support and we are overwhelmed!

The people around you often don't get involved because of ignorance about your loved one's actual needs, meaning that they have no idea about all the care and assistance that he requires. They may also believe that you are doing very well or that you don't want help! Contrary to what you may think, others cannot guess your needs.



To get the help that you want, you must express what you feel as well as your expectations for support. Despite all the good will in the people around you, you must accept that everything is not necessarily done according to your requirements and your way of doing things. Consequently, it may be difficult for you at the beginning to ask for help. On the other hand, it will allow you to "recharge your batteries." And sometimes, despite specific requests, your family members may refuse to help you. In this case, tension and family conflicts can arise, which of course you want to avoid, sometimes at any price! What mainly counts is how you and the other person manage to resolve your differences. Your common goal is to arrive at an agreement so that you can make positive changes for the benefit of the person being helped.

First and foremost, be well informed

Very few caregivers have received training to take care of their loved one who is losing his autonomy. They may feel increasingly needy and powerless. Health professionals from different organizations are noticing that one of the most important shortcomings with caregivers is a lack of information about the health of the person being helped. To explain to you in a concrete way how having proper information can be useful, and even indispensable, here is an excerpt from the document *L'Entourage* produced by the Regroupement des aidants et aidantes naturels de Montréal (R.A.A.N.M., Coalition of Caregivers of Montreal):

"Learn about the possible evolution of the disease and its consequences over time. The more you know, the more you will be able to identify what you can do for your loved one and, as a result, establish your limits. It goes without saying that when a specific diagnosis is given, you may be shocked. This is completely normal. It is important to take the time necessary to feel the emotions that accompany the news about a loved one. This news will without a doubt upset his life as well as yours.

It would be useful for you to try to obtain information and knowledge from caregiver groups, and from the different community organizations and health institutions. Depending on the case, this knowledge can enlighten you about the approach to take with elderly people or about the evolution of the disease. This will help you better understand the person that you are taking care of and adjust your way of providing care in relation to his needs. You will be better equipped to adapt to changes if you understand that they are the characteristics of your loved one's disease. In the same way, you will be even better able to anticipate events, to follow more serenely the stages and progression of the disease, and to plan beforehand if you become informed about his problems. You will also have the advantage of better understanding his behaviour. For example, a person with cognitive deficits is not doing it on purpose when he asks you the same question ten times. He is doing it because he is confused and suffers from memory loss.

After having gathered all the useful information, you will be able to pass it on to the members of your family at the appropriate time. You can inform them properly about your relative's disease, the care to give to him, and the consequences of his disease over the short and long terms." (Free translation)

Inform the person being helped

Making changes to avoid exhaustion involves changes in the care to be given to your loved one. Actually, your loved one must accept that someone other than you will provide care to him. Your loved one may have already made you aware that he does not want help from strangers, or perhaps you do not dare consult him because you are afraid that he will feel intimidated or abandoned by you. However, the situation has a solution. It is important to make your loved one aware of what you are feeling and to express your needs to him in a clear way.

Trying something new does not necessarily mean adopting it. You can always readjust yourself as you go along. The important thing is to be able to establish good communication between you and the person being helped, whenever possible.

It may be difficult to establish good communication, particularly if the person being helped has cognitive deficits. Organizations such as the Alzheimer Society, the Parkinson Society, and ALPA can help you better communicate with your loved one.

Inform your family and your relatives

To obtain your family's moral and physical support, you must take some time beforehand to stop and take stock of your situation. We suggest that you put down on paper everything you are doing, and that you identify your needs. This assessment will be useful to you when you share the tasks with the members of your family and people close to you. (See quick reference in the information pocket). Why not ask them to:

- Run errands;
- Prepare frozen meals;
- Take care of his clothing or do his housekeeping;
- Accompany the person being helped to his medical appointments;
- Replace you during your outings or your holidays?

Learning to delegate one or more tasks will help you reduce the pressure that you feel and will allow you to take time to take care of yourself.

"One afternoon per week, a family member comes to my home to take care of my father. During this time, I wander through the stores, have a coffee at a friend's place... My afternoon is for me and I often don't come home until supper, which is prepared for my father. An afternoon just for me! It is my "boost" to continue."

Seeking help from your close relatives is sometimes difficult for several reasons. In this case, it may be useful to call a family meeting.

"My mother wanted to stay as long as she could in her home, and this was also what I wanted. A family meeting with a social worker from the CLSC was organized in my mother's home, and this helped us all very much. The social worker explained my mother's real needs to us and what we could all do, including my mother, to respect her wishes as long as possible. Then, it was easier to delegate the tasks to family members and to receive outside help."



3

The caregiver and placement of a loved one



"The caregiver has to accept that she is not the only one capable of properly caring for the person receiving care."
(A health professional)

Preparing yourself for the placement of a loved one

"Taking care of a loved one who is losing his autonomy can sometimes require us to make very agonizing and upsetting decisions."

For different reasons, the caregiver must seek out new resources in order to improve her loved one's quality of life and perhaps even her own quality of life.

The move towards placement marks a transition for the caregiver and the person being cared for, and not a separation. You and your loved one want to maintain the link joining you. You can still support your loved one, but in a new context of help. However, you will need some time to adapt to this new situation.

Your role as a caregiver will change but will still remain important. In fact, your collaboration will be invaluable. You can help your loved one adapt to his new residence because you know his tastes, interests and habits well. Inform the staff about them. This will make your loved one's adaptation much easier. For you, it could be difficult accepting that someone other than you will provide care for him. If you want to, why not give your loved one some of the care, with the agreement of residence personnel?

At this stage, your loved one will really appreciate your moral support and your warm presence. Continue to visit him regularly, even if your relationship is sometimes delicate. Remind yourself that placement is a change for him. He will need some time to adapt and become familiar with his new surroundings and with new people.

Your loved one will always need human contact, even if he forgets a few names and a few faces... To help you continue to be involved with your loved one, most residences have an activity department and a volunteers' committee that you can join. By accompanying your loved one in an activity that he likes, you can share happy moments together.

Give yourself time to adapt to your new role

The integration and adaptation process will happen slowly. Don't forget that after all these years, you have become accustomed to this shared presence. Think about all the time that you spent meeting the needs of your loved one and ensuring his well-being during a week or even a day. His placement will undeniably change how your life is organized. It is important to take care of yourself, to give yourself ways to feel good in your heart and in your head. Fill your free time in a rewarding way and maintain contacts with people other than the person being helped and the people around him. Once again, you are the one that knows best what to do to take care of yourself.

Placement frees caregivers from an often overly demanding responsibility, but for many of them, it symbolizes abandoning a loved one and the feeling of having failed in their role. As a result, you may feel a lot of emptiness in your life as well as shame, guilt and worry, after entrusting your loved one to an outside resource. This is completely understandable. You too will have to adapt. Don't hesitate to share your feelings with a person with whom you are comfortable. You can also make use of caregiver groups or even the resources available to support you and to accompany you in this difficult situation.

Some caregivers can feel that they are abandoning their loved one or that they are not fulfilling their commitment, even if they know that keeping the person at home is no longer possible. But... turning to placement resources is, in a sense, making your loved one your primary concern.



4

Resources for you



"To be a "good" caregiver, love is not enough..."
(A health professional)

The Centre de santé et de services sociaux (CSSS) de Laval

Social workers

The Centre de santé et de services sociaux has competent people among its employees who can offer the help and the services that you need.

A social worker is a professional in the help relationship. He is familiar with the different resources in the community and works with them to best meet your needs.

When you are living through difficult times, when a death occurs, when you are exhausted, when you wonder about your role as a caregiver, when one of your loved ones has physical or cognitive difficulties, you can turn to your social worker and receive psychological, moral and educational support.

The social worker works not only with the person requiring care, but also with his caregivers. It is therefore the social worker to whom you must turn for answers to your questions. Your social worker becomes the gateway to the different services offered by the government and many community organizations in your district. This professional can also accompany you in the legal procedures that your situation may require.

You can contact a social worker by calling the Centre de santé et de services sociaux de Laval.

TO REACH THE UNIVERSAL ACCESS TO THE CSSS DE LAVAL, THERE IS JUST ONE NUMBER TO REMEMBER: 450-622-5110, EXT. 4922

CSSS home care services

The purpose of home care is to make up for the temporary or permanent loss of autonomy of the person you are helping in carrying out his daily, domestic and social activities. This service is supplied following a needs assessment done by the health professional responsible for your file at the CLSC, your navigator. Here are a few examples of services:

- Hygiene care;
- Dressing;
- Supervision of medication;
- Support and supervision during meals (heating already prepared meals);
- Respite, day care (when the user cannot be left alone), to allow the caregivers a few hours a week to carry out certain tasks or to take part in an activity. Several community resources now offer respite services meeting different needs;
- Supervision for an exercise program for the person being helped (following an assessment by the physiotherapist).

Professional services

- Nursing care
- Medical care
- Psychosocial follow-up
- Occupational therapy
- Physiotherapy
- Nutrition
- Evaluation by a pharmacist

Day centre (clientele losing their autonomy related to aging)

Day centres offer therapeutic and preventive activities for people losing their autonomy and allow caregivers free time.

Temporary placement

This program is offered by your Centre de santé et de services sociaux and follows a psychosocial assessment. It offers caregivers the possibility of some free time (holidays, visiting family, or free time at home) by placing their loved one for a few days. In 2008, the cost of a bed in temporary respite was \$15/day. A person can take advantage of it for up to 8 weeks of respite per year.

Target clientele

- Adults losing their autonomy.

Equipment loan service

- Following an assessment, the navigator makes the request (if the equipment is not covered by the person's insurance company);
- Loan for approximately 3 months (there are some costs involved);
- If the disability is major and permanent, a grant application can be submitted for a hospital bed, for example;
- If the equipment costs less than \$100, the person is encouraged to purchase it (e.g., raised toilet seat);
- Wheelchairs and walkers are supplied by RAMQ after an assessment at the Laval Jewish Rehabilitation Hospital.

Programme d'aide aux personnes handicapées (Assistance program for the disabled)

This program is intended for people with a physical, organic or intellectual disability and who meet the legal definition in the Act to secure handicapped persons in the exercise of their rights.

Programme d'organisation des services intensifs long terme pour personnes handicapées (P.O.S.I.L.T.P.H., intensive long-term services for disabled people)

Services offered

- Personal assistance: basic hygiene, nutritional, transfer, and dressing assistance.
- Home assistance service: housekeeping (3 hours every 2 weeks), menu preparation, laundry.
- Civic support (for example, help in filling out a form).
- Assistance service: between 5 and 44 hrs / week.

Target clientele

- Any person under 60 years of age who is recognized as a disabled person under the definition of the Act.
- Autistic and invasive developmental disorders.

Support for the family

Services offered

Grant for:

- Respite: planned approach intended to provide rest for the family and allow them to regain their strength (e.g., weekend holiday, day camp, etc.).
- Day care: to compensate for the "abnormal" load of care and responsibility related to the disabled person's disabilities (e.g., after school, during pedagogical days and school breaks).
- Emergency assistance: supervision during emergency and unexpected situations; parents have to be replaced, maximum period of 2 weeks (e.g., during hospitalization of the parent).
- Assistance in parental roles: series of measures intended for disabled parents with children under 12 years of age, so that they can assume their parental roles (e.g., assistance taking care of their children {hygiene, meals, homework, babysitting }).

Target clientele

- Disabled children and adults (under 60 years of age) with a motor, organic, sensory, intellectual or physical disability and living at home.
- Disabled parents or guardians with a child under 12 years of age.
- Autistic and invasive developmental disorders.

Transport*

Services offered

- Grant for travel for the following situations:
 - Early stimulation centre (children 0-5 years of age).
 - Repeated hemodialysis treatments.
- Intensive treatments for:
 - Cystic fibrosis;
 - Chemotherapy (starting with the 11th treatment);
 - Laryngectomees (Pavillon Notre-Dame CHUM).
- Repeated rehabilitation treatments (speech therapy, occupational therapy, physiotherapy, etc.) related to the disability.
- Requests for cochlear implants.

* 60% reimbursement for kilometres travelled and parking.

Target clientele

- Children and adults with a motor, organic, sensory, intellectual or physical disability.
- Autistic and invasive developmental disorders.

Instrumental activities of daily living (IADL), activities of domestic life (ADL)

Services offered

- Purchase of technical aids that can improve autonomy, compensate for disabilities.
- Instructions for the user and follow-up with occupational therapy when required.
e.g., equipment for hygiene care, hoist, hospital bed...

Target clientele

- Anyone recognized as a disabled person according to the definition in the Act.
- Autistic and invasive developmental disorders.

Elimination function

- Grant for the purchase of incontinence briefs (max. 6 per day), day and night pads (max. 6 per day), washable piqués (3 to 6 per year). Purchase and transport management organized by the CLSC for child, adolescent and adult clientele.
- Grant for medical supplies: home catheter stand, bladder irrigation, bladder or intestinal voiding, long-term wound care according to prescription, tracheotomy.
- Reevaluation of needs once per year.

Target clientele

- Anyone 3 years of age or older who is recognized as a disabled person according to the definition in the Act.
- Clients with a diagnosis of Alzheimer's and severe dementia.
- Autistic and invasive developmental disorders.

Placement

The social worker proceeds to evaluate the autonomy of the person being helped. The attending physician must also complete a medical assessment. Subsequently, the social worker forwards these forms to the CSSS de Laval's regional admission system. The regional admission committee meets to study the file. A referral to an institution that corresponds to the person's needs is then proposed.

If the person being helped has suffered a great loss of autonomy, he will be directed towards a CHSLD. However, if his loss of autonomy is somewhat less, he could be directed towards an intermediate resource.

The individual is then put on a waiting list. Admission is done on a chronological basis. Should there be an emergency that requires immediate placement, an interim bed is then proposed.

Target clientele

- Adult losing his autonomy.

Cost

The cost of a public residence is based on the person's income. In 2008, the maximum monthly financial contribution was:

- | | | |
|---------------------------------|-------------------|--------------|
| • Long-term care | private room | : \$1,590.90 |
| | semi-private room | : \$1,329.90 |
| • Allowance (personal expenses) | | : \$183.00 |
| • Intermediate resources | | : \$1,053.00 |
| • Allowance | | : \$180.00 |

For more information: RAMQ 514-873-1529
For all other clients, contact the social worker.

Community and other organizations

In addition to your close family and friends and the CSSS, there are resources in your community that can provide you with considerable support. Some non-profit organizations in the community offer services that meet specific needs.

For example: The Association Lavalloise des Personnes Aidantes, Meals on wheels, Centre d'action bénévole, Coop de soutien à domicile, etc.

The information pocket contains a complete list of community and public resources in your region.

Respite for caregivers

We want to mention in particular some respite programs offered to elderly clientele.

- Ce répit m'appartient: home respite service offered by the Association Lavalloise des Personnes Aidantes, in collaboration with the Coopérative de soutien à domicile de Laval.
Information: 450-686-2572
- Centre d'animation Pierre A. Grothé and temporary placement: service offered by the Société Alzheimer Laval.
Information: 450-975-0966
- Self-paced respite: service offered by the Escale du Rendez-vous des aînés community centre.
Information: 450-667-8836
- Temporary placement: offered by the Regroupement Lavallois des Chambres et Pensions pour Personnes Âgées.
Information: 514-993-2237
- Companion service at home: service offered by Baluchon Alzheimer, for a period of 7 to 21 days.
Information: 514-762-2667

Conclusion

Studies show it and we have already said it: Families provide approximately 80% of the services and care required by the elderly. It is a myth to believe that family solidarity no longer exists (Garant and Bolduc, 1990).

Québec, just like Canada, prefers dependent people being kept in the community. The resources allocated to these services have never met the needs. Since the end of the 1980s, deinstitutionalization and the shift to ambulatory care have drawn attention to the major role of families in the management of dependent people.

The increasingly visible presence of caregivers in the public arena demonstrates the dynamism of these family solidarities. In such a context, many people will choose to become caregivers. The motivations that lead you to become a caregiver vary. Whether they are of a practical, affective, relational, moral, social or philosophical nature, they all remain important. To continue to play your role of caregiver effectively, you must take care of yourself and respect your limitations.

If you are worn out, this document shows that you are not alone. As a result, we can't encourage you enough to ask for help. Several possibilities are open to you. You just have to talk about it.

A good idea would be to become a member of a caregiver network such as ALPA, which provides you with access to information, services and activities that will be of great help to you when you need them.

**Caregivers do not want to be replaced;
they want to be supported.**



Bibliography

BELLEAU, H., Saint-Laurent, C., 2005: La décision d'hébergement des personnes âgées en institution: le point de vue des différents acteurs. In.: Ouellette, F.-R., Joyal, R., Hurtubise, R. Familles en mouvance: quels enjeux éthiques? Les Presses de l'Université Laval, p. 317-332.

BROUILLETTE, Angèle-Aimée, 2005: Plan d'action régional 2005-2006 sur les services destinés aux personnes âgées en perte d'autonomie. Volet proches aidants, Rapport de la consultation menée au Centre de santé et de services sociaux du Grand Littoral, Agence de la santé et des services sociaux Chaudière-Appalaches, 27 p.

CLSC-CHSLD Haute-Ville-Des-Rivières: Aider sans se rendre malade, Guide d'information à l'intention des PERSONNES AIDANTES, 19 p.

DUCHARME, F., G. PÉRODEAU, M. PAQUET, A. LEGAUT and D. TRUDEAU, 2003: Virage ambulatoire: perceptions et attentes envers les services destinés aux aidants familiaux de personnes âgées, Chaire Desjardins en soins infirmiers à la personne âgée et à la famille, 69 p.

DUCHARME, F., LÉVESQUE, L. et al., 2003: Prendre soin de moi! Programme d'intervention destiné aux aidantes d'un proche hébergé présentant des déficiences cognitives. Institut universitaire de gériatrie de Montréal.

DUCHARME, F., 2006: Familles et soins aux personnes âgées, enjeux, défis et stratégies. Montréal, Beauchemin, 210 p.

GUBERMAN, Nancy, Jean-Pierre LAVOIE and E. GAGNON, 2006: Valeurs et normes de la solidarité familiale: statu quo, évolution, mutation?, Centre de santé et de services sociaux Cavendish, 101 p.

GUBERMAN, Nancy, P. MAHEU and C. MAILLÉ, 1991: Et si l'amour ne suffisait pas. Femmes, familles et adultes dépendants, Montréal, Remue-ménage.

GUBERMAN, Nancy, 2004: "Non, l'amour ne suffit pas! Soigner ses proches", Revue Notre-Dame, p. 15-28.

LAVOIE, J.-P., 2005: Prendre soin d'un proche âgé, Paris and Montréal, Érès.

MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX, 2003: Chez soi: le premier choix. La politique de soutien à domicile, 43 p.

ORZECK, Pam, Nancy GUBERMAN and Lucy BARYLAK, 2001: Des interventions novatrices auprès des aidants naturels, CLSC René-Cassin-Institut de gérontologie sociale du Québec, Éd. Saint-Martin, 171 p.

PAQUET, Mario, 2003 : Vivre une expérience de soins à domicile, Presses de l'Université Laval, coll. Mutation, 230 p.

REGROUPEMENT DES AIDANTES ET AIDANTS NATURELS DE MONTRÉAL, 1997 : Roue de Secours, Document de soutien pour les aidantes, Montréal.

REGROUPEMENT DES AIDANTES ET AIDANTS NATURELS DE MONTRÉAL, 2004 : LA BOUSSOLE. Pour ne pas la perdre quand on s'occupe d'un proche. Guide des droits, des services et des ressources, 98 p.

REGROUPEMENT DES PROCHES AIDANTS DE BELLECHASSE, 2002 : "Prendre soin de moi tout en prenant soin de l'autre", Guide d'accompagnement à l'intention des personnes aidantes, 55 p.

REGROUPEMENT DES ASSOCIATIONS DE PERSONNES AIDANTES NATURELLES DE LA MAURICIE, 2006. "Prendre soin de moi tout en prenant soin de l'autre". Guide de prévention de l'épuisement destiné aux proches aidantes et proches aidants, 47 p.

VACHON, Marc : "C'est pas parce que c'est drôle qu'on rit, mais quand on rit...", Website: www.oserchanger.com/rire.php.

VERGARA, A. and OUMET, K., 2005 : "Prévenir l'épuisement des aidants naturels", Association des familles soutien des aînés de St-Hubert.

Useful references

THE CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION. Living lessons. About quality of life for the last stages of life, 2002.

CENTRE COMMUNAUTAIRE LE COUMBITE DE LAVAL. Directory of resources for the elderly in Laval, édition 2006.

EMPLOI QUÉBEC. Répertoire des organismes de Laval, édition 2007.

FORTIN, B. Le bonheur: la quête de toute une vie! Website: www.psychologue.levillage.org.

FORTIN, Bruno and Sylvain NÉRON. Vivre avec un malade sans le devenir, Bartholome éd., 1998.

FOURNIER, Édith. J'ai commencé mon éternité, Éd. De L'Homme, 2007.

GENDRON, Marie and Denis **GAUVREAU**. Questions et réponses sur la maladie d'Alzheimer, Éd. Le Jour, 2007.

INSTITUT UNIVERSITAIRE DE GÉRIATRIE DE MONTRÉAL. Website: www.aidant.ca.

KUBLER-ROSS, Élisabeth. Leçon de vie, J.C. Lattès, 2002.

MONBOURQUETTE, Jean. À chacun sa mission. Découvrir son projet de vie, Novalis, 2001.

MONBOURQUETTE, Jean and Denise **LUSSIER-RUSSELL**. Mourir en vie. Le temps précieux de la fin. Novalis, 1995.

POLETTI, R. and **DOBBS**, B. Vivre son deuil et croître, Genève, Jouvence, 1993.

POLETTI, Rosette and Barbara **DOBBS**. La compassion pour seul bagage, Éd. Jouvence, 2004.

POLETTI, Rosette and Barbara **DOBBS**. Prendre soin de soi pour prendre soin de l'autre. La voie du coquelicot, Éd. Jouvence, 2003.

VETERANS AFFAIRS CANADA. "Care for the Caregiver" Manual.
Website: www.vac-acc.gc.ca/general

VANIER, Jean. Toute personne est une histoire sacrée, Plon, 1994.

Videos

Aider sans se rendre malade. CLSC-CHSLD Haute-Ville-Des-Rivières, 30 min.

Baluchon Alzheimer. Un service novateur de répit et d'accompagnement à domicile.
Réalisation Jean-Pierre Lefebvre, 2003. 21 min.

Édith et Michel. Réalisation Jocelyne Clarke, Les Productions Érézi Inc. and ONF, 2005. 54 min. 47 sec.

Prendre soin de soi tout en prenant soin de l'autre. Réalisation Patrick Damien Roy, Regroupement des proches aidants de Bellechasse, 2003, 25 min.



ASSOCIATION LAVALLOISE DES PERSONNES AIDANTES

1717, boul. St-Martin ouest, bureau 350 A
Laval (Québec) H7S 1N2

Téléphone: 450-686-2572
Télécopieur: 450-686-2503
Courriel: alpa@bellnet.ca
Site Internet: www.aldpa.org