

NATURAL CAREGIVERS : A GUIDE FOR THE FIRST NATIONS OF QUEBEC



FIRST NATIONS OF QUEBEC AND LABRADOR
HEALTH AND SOCIAL SERVICES
COMMISSION

MARCH 2009

Coordination : Kathleen Jourdain

Research and editing : Judith Petitpas

Translation : Alpha Traduction

Design graphic : Marcel Robichaud

Printing : Les Copies de la Capitale inc.

Acknowledgement : We wish to thank Health Canada for it's financial contribution to the project.

Adaptation : Please note that the information contained in this guide may be taken from various web sites.

ISBN 978-1-956553-05-4

TABLE OF CONTENTS

Introduction	4
Why produce a natural caregiver guide for the First Nations of Quebec?	4
Who is the guide intended for?	4
What is the FNQLHSSC?	5
1. Natural caregiver—who, me?	6
1.1 What is a natural caregiver?	6
1.2 Am I the only one in this situation?	6
1.3 What are the roles of the natural caregiver?	6
1.4 What can I expect?	7
2. What can I do to adjust to this new role?	9
2.1 Develop self-esteem	9
2.2 Be assertive	10
2.3 Recognize signs of burn-out	10
2.3.1 Physical symptoms	11
2.3.2 Psychological symptoms	11
2.4 Understand the feeling of guilt	11
2.5 Ask for help	12
2.6 Face the trials of life	14
3. How to recognize abuse?	16
3.1 Psychological abuse	17
3.2 Economic abuse	17
3.3 Physical abuse	17
3.4 Sexual abuse	18
3.5 Violation of rights	18
3.6 Neglect	19
3.7 Relational abuse and verbal abuse	20
4. What about drugs, medication and alcohol?	21
5. What resources are available?	23
5.1 Resources for natural caregivers	23
5.2 Resources for seniors	25
5.3 Resources for people with disabilities	25
5.4 Resources on violence	25
5.5 Resources on Alzheimer’s	26
5.6 Resources on cancer	26
5.7 Palliative care and end-of-life resources	26
Conclusion	27
Annex A A caregiver’s bill of rights	28
Annex B Caregiver checklist an important tool	29
Personal Notes	35

INTRODUCTION

FIRST OF ALL, THANK YOU FOR BEING A CAREGIVER; YOU ARE MAKING A VALUABLE CONTRIBUTION AND DIFFERENCE.

WHY PRODUCE A NATURAL CAREGIVER GUIDE FOR THE FIRST NATIONS OF QUEBEC ?

As a result of the move toward outpatient care in the 1990s and the political will to reduce congestion in the hospitals, more and more people are receiving care at home. This means that a greater number of people have had to take charge of a family member living with reduced autonomy.

This reality is also being felt in the First Nations of Quebec, with the notable difference that fewer services and support measures are available to First Nations natural caregivers, largely due to a lack of resources within our communities.

In response to a situation that is affecting more and more members of the First Nations, this guide was designed to provide support and tools for natural caregivers in the care they provide to their family members.

WHO IS THE GUIDE INTENDED FOR?

This document was created for natural caregivers, their families and their support network, to provide information about the various aspects of their role. It was also designed to help people make decisions they will be confronted with as they embark on the journey of giving care to someone who depends on their help.

The objectives of this guide are to provide information about the various subjects and concerns that affect family caregivers, to encourage them, to validate and support their role, and finally to increase their awareness and understanding of their responsibilities.

INTRODUCTION (CONT'D)

WHAT IS THE FNQLHSSC?

The First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) is a health and social services organization that supports the First Nations communities of Quebec and Labrador. It was established in 1994 by the Chiefs of the Assembly of First Nations of Quebec and Labrador (AFNQL) and is directed by a Board of Directors with seven elected members.

The Commission's vision and mission is to promote and monitor the physical, mental, emotional and spiritual well-being of First Nations and Inuit people, families and communities while improving access to comprehensive and culturally-sensitive health and social services programs designed by First Nations organisations that are recognised and sanctioned by local authorities, all the while respecting their respective cultures and local autonomy. The Commission also assists communities that so desire, to set up, develop and promote global health and social services and programs that are adapted and conceived by First Nations organisations.

1

NATURAL CAREGIVER – WHO, ME?

1.1 WHAT IS A NATURAL CAREGIVER?

A natural caregiver is a person who provides support and assistance to a family member, friend, neighbour or anyone else who needs help. The cared-for person may be a child, an adult or a senior. The natural caregiver helps the person do all kinds of tasks and activities. The assistance may be required more or less often and it is always unpaid.

A number of terms are used to define a natural caregiver such as: natural aid, informal caregiver, family caregiver, substitute caregiver, non-professional caregiver, and support person. These are all synonyms for natural caregiver.

1.2 AM I THE ONLY ONE IN THIS SITUATION?

No, you are not alone. According to the Quebec Ministry of Health and Social Services, about 10% of the Quebec population provides assistance to someone with a long-term disability. The percentage of Aboriginals who are natural caregivers is hard to estimate, but in 2005, Indian and Northern Affairs Canada listed 78,940 Aboriginals living in Quebec. At 10%, this would mean over 7,800 Aboriginals are serving as family caregivers.

In addition, according to the Assessment of Continuing Care Requirements in First Nations and Inuit Communities, three-quarters of family caregivers are women¹.

Finally, in the years ahead, the demand for family caregivers is expected to increase, due to our aging population, the decrease in family size, and the increase in disabling diseases².

1.3 WHAT ARE THE ROLES OF THE NATURAL CAREGIVER?

According to the Quebec Ministry of Health and Social Services³, people who help another person living with a loss of autonomy fulfill several functions in society.

First of all, they are citizens with personal, social, professional and family responsibilities.

¹ FNQLHSSC, 2006. *An Assessment of Continuing Care Requirements in First Nations and Inuit Communities*.

² FNQLHSSC, 2006. *An Assessment of Continuing Care Requirements in First Nations and Inuit Communities*.

³ Ministère de la Santé et des Services sociaux, 2003, *La politique de soutien à domicile : Chez soi le premier choix*.

Then they are natural caregivers who freely, voluntarily and knowingly agree to make a commitment to the cared-for person.

Through this commitment, natural caregivers become health and social services clients themselves, and it is natural for them to need support and coaching to fulfill their roles.

Finally, by helping someone living with a loss of autonomy, natural caregivers become the partners of the professionals who are also taking care of that person. It is important that these caregivers, with the consent of the cared-for person, receive the information, training and supervision required to fulfill the tasks they have agreed to take on.

1.4 WHAT CAN I EXPECT?

Being a natural caregiver is not simply a matter of carrying out a series of tasks that the cared-for person is no longer capable of doing. It entails a real relationship with the person, where roles are sometimes reversed. A deep relationship that includes a history, intimacy and also irreversible losses, the suffering of both parties and the possibility of losing someone you love⁴. Everyone experiences this relationship differently. Taking care of someone demands time and energy. It is also possible that the scope of the assistance the natural caregiver has to provide will increase as the health of the cared-for person deteriorates. It is to be expected that this situation will have a huge impact on the life of the caregiver.

The extent of the impact depends on several factors, especially time, and it goes without saying that the more hours spent helping the cared-for person, the greater the impact will be on the caregiver's life. Likewise, the longer the person requires care, the greater the impact is on the caregiver as well.

Natural caregivers may feel that their commitment to the cared-for person is having repercussions on their own family and marriage. In some cases, the loss of autonomy draws people together and tightens family bonds. In other cases, when the main caregiver has little support from the other members of the family, conflicts may arise, spread, worsen, or explode⁵.

⁴ Conseil des aînés, 2008, *Avis sur l'état de situation des proches aidants auprès des personnes âgées en perte d'autonomie*, Government of Quebec

⁵ Conseil des aînés, 2008, *Avis sur l'état de situation des proches aidants auprès des personnes âgées en perte d'autonomie*, Government of Quebec.

In addition, time spent on social activities is often diminished to support the cared-for person. Depending on the extent of the commitment they make, natural caregivers may begin to feel isolated. The same may happen on the job, as their careers are often disrupted or even brought to a virtual halt. The frequent absences, underperformance, and increased stress may require a complete reorganization of the natural caregiver's professional life.

Finally, the effects of caring for another person may also be felt in the caregiver's own physical and mental health. As they become more tired, caregivers are more susceptible to illness. The symptoms caregivers suffer may include an increased need for medication, trouble sleeping, headaches, fatigue, and loss of energy or weight. On the emotional front, stress, impatience, frustration, anxiety, insecurity, unhappiness, discouragement, guilt, and helplessness are all problems that natural caregivers experience.

Despite all this, it is important to say that caregiving can be a very rewarding experience in human terms. Many natural caregivers discover talents they did not know they had, and many develop deep and gratifying relationships with the people they are caring for. People who take on this role often speak of it as a positive, intense and profound experience. Being a natural caregiver may result in significant benefits, such as improved interpersonal relationships between the caregiver, the cared-for person and the family and support network, the satisfaction of doing valuable work, the feeling of meeting the needs of a loved one, a better understanding of your loved one, better self-esteem, and a heightened sense of your own self-worth. Being a natural caregiver also gives you an opportunity to create a new relationship with your loved one and with your family and support network, to return love you have received, to develop new skills and new knowledge and to create memories. This experience also gives rise to feelings of accomplishment, compassion, joy and an appreciation for life⁶.

⁶ Manitoba Seniors and Healthy Aging Secretariat, 2008, *A Guide for the Caregiver*.

The way you fulfill your role as a natural caregiver depends largely on your perception of and interest in the role. The more positive your perception and the greater your interest in taking care of the person, the more the role will seem natural. On the other hand, if your perception is negative and your interest is low, the task will seem more difficult.

The way you fulfill the role also depends on your ability to recognize and respect your own limits. In its document for natural caregivers, the Centre-Ressources pour la Vie Autonome⁷ (Resource center for an autonomous life)* identifies several things that will help you carry out this role: develop self-esteem, be assertive, recognize signs of burn-out, understand the feeling of guilt, ask for help and be prepared to face the trials of life.

2.1 DEVELOP SELF-ESTEEM

First of all, it is important for you to develop your self-esteem. Having self-esteem means acknowledging your ability to rise to the challenges of life and considering yourself to be worthy of happiness⁸. To succeed in life and find it fulfilling, natural caregivers need to believe in their own abilities. The role you are playing for your loved one may be difficult, and you will need all your personal resources to fulfill it. So it is important for you to take the time to look after your self-esteem. You are competent, and you are doing your best to help your loved one: this is what you must remind yourself. The *Guide d'accompagnement et d'information pour les aidants naturels* (accompanying guide and information for natural aids)*, (in French only) is a good tool to help you start thinking about your self-esteem.

⁷ Cécily Trudeau and Isabelle Chassé, 2006, *Guide d'accompagnement et d'information pour les aidants naturels*, Centre-Ressources pour la Vie Autonome : Région Bas-Saint-Laurent.

⁸ Nathaniel Branden, 2003, *L'estime de soi : une force positive. Un regard sur notre ressource psychologique la plus importante*, Éditions Sciences et Culture, Montréal.

* Free translation.

2.2 BE ASSERTIVE

Being assertive is one way of recognizing your own limits. Being assertive means expressing your opinion, feelings and needs while respecting those of others⁹. People are afraid to be assertive for many different reasons. You may be afraid of disappointing, displeasing or hurting someone. You may be afraid of being rejected or losing the love of the people close to you. You may be afraid of not meeting people's expectations, or you may feel selfish if you say no. You may be afraid of seeming critical or creating conflict. All these feelings are legitimate and natural. But you have the right to express your emotions and opinions. When you assert your own needs, you are respecting your limits and reducing the risk of burn-out. It is highly likely that the person you are taking care of loves you and does not want you to burn out. So learn to express your real emotions and opinions using sentences that start with "I." The *Guide d'accompagnement et d'information pour les aidants naturels (Accompanying guide and information for natural aids)** offers some interesting exercises for learning how to express your emotions in a way that respects your limits and those of the people around you.

2.3 RECOGNIZE SIGNS OF BURN-OUT

Burn-out can be triggered by the excessive demands that we place on ourselves or that are imposed from the outside (family, work, friends, romantic relationship, value system or society) and that weaken our strength, our defence mechanisms and our resources¹⁰. You can't learn to be a natural caregiver from one day to the next. Being a caregiver means learning a number of different tasks that may be very stressful. This situation can give you the impression of playing several roles at once: nurse, psychologist, cook, advisor, and so on. Always putting the needs of the cared-for person first may lead you to start to ignore your own needs. Slowly but steadily, physical and psychological fatigue sets in and burn-out is right around the corner. These are signs you cannot ignore, because the physical and psychological consequences can be severe.

⁹ Cécily Trudeau and Isabelle Chassé, 2006.

¹⁰ Catherine Lord, 1988, "Les douze phases du burn-out," in *La Gazette des femmes*, December-November issue.

* Free translation.

2.3.1 PHYSICAL SYMPTOMS

If you notice unusual or unexplained physical conditions, it is important to pay attention to them. These signs may be pains of various sorts, headaches, increased fatigue, loss of energy, problems sleeping, gastro-intestinal problems, weight loss, etc. It may be harmless, but it may also be the sign of a more serious problem.

2.3.2 PSYCHOLOGICAL SYMPTOMS

Likewise, if psychological conditions become apparent, it is important to listen to your symptoms. These problems could be expressed as impatience, frustration, anger, anxiety, insecurity, worry, sadness, discouragement, guilt, low self-esteem, a feeling of incompetence, helplessness or inability to concentrate. In other words, your behaviour changes and you feel as if you don't know yourself. These are signs you should pay attention to, because they too can have serious consequences that include depression, suicidal thoughts or even attempted suicide. You should not keep these thoughts to yourself.

There is a risk that family caregivers will stop providing care because of a lack of support or due to feelings of distress, anger or depression. So if physical or psychological symptoms start to appear, consider it a warning: consult a health care or social services professional immediately.

2.4 UNDERSTAND THE FEELING OF GUILT

First we should differentiate between guilt, which is the result of doing something that is against the law, like hitting someone, and feeling guilty, which is when you feel you have done something wrong or not lived up to your own expectations or the expectations of others¹¹. This is a very subjective feeling that differs from person to person and is rooted in individual values. Family caregivers often feel guilty because they are so used to putting the needs of others ahead of their own that sometimes when they finally do something for themselves, they are overwhelmed by feelings of guilt. Feeling guilty can also be the result of acting against your own values or principles, of being constantly questioned by the people around you, or of not taking responsibility for your own actions or choices.

¹¹ Cécily Trudeau and Isabelle Chassé, 2006, *Guide d'accompagnement et d'information pour les aidants naturels*, Centre-Ressources pour la Vie Autonome: Région Bas-Saint-Laurent.

Guiltiness is a very negative feeling because it destabilizes you and makes you question all your decisions. If you feel paralysed by guilt, it is important to ask yourself some questions to clarify your thoughts and your situation.

Ask yourself whether your actions reflect your values and personal convictions. If so, take responsibility and explain yourself firmly and with conviction. If not, ask yourself what you wish you had done and think about what you can do to change your actions in the future. You can also ask yourself whether, to the best of your knowledge, you did what was best for yourself and for the others involved. If so, you have no reason to feel guilty.

2.5 ASK FOR HELP

The family caregiver is often the only person responsible for all the care needed by the person in question. While this situation may make you feel valuable and responsible in the short term, it can be a double-edged sword...

There may be many reasons for taking on the entire responsibility of family caregiver alone. You may want to be independent and not owe anyone anything. You may think you are the only person capable of taking care of the person. You may want to hide your vulnerability so no one thinks you are weak. You may be afraid that others will refuse to help you. You may feel that outside help is an intrusion in your privacy or the privacy of the person you are caring for. You may think no one has time to help you. The person you are caring for may have a sense of modesty and not want anyone else to help. You may want to be seen as a hero or victim in the situation or it may make you feel valued or proud to be the only caregiver.

One thing is certain: no matter what your reason is, taking sole responsibility for all of the care is very risky, because sooner or later, it will lead to burn-out¹².

It is important for you to learn to ask for help as soon as you start caring for someone who is living with a loss of autonomy. Asking for help does not mean you are not capable of taking responsibility. It means that you understand your own needs and those of the person you are caring for. In fact, it demonstrates your wisdom.

¹² Cécily Trudeau and Isabelle Chassé, 2006, *Guide d'accompagnement et d'information pour les aidants naturels*, Centre-Ressources pour la Vie Autonome: Région Bas-Saint-Laurent.

Don't fool yourself into thinking that you are "essential" and that no one else can learn the role of caregiver. You learned, so someone else can too. Remember that there is strength in numbers, and that may lighten the workload. Finally, don't be discouraged if some people refuse to help you. Everyone is free to agree or refuse to help. If someone says no, turn to someone else. Somewhere there is someone who will be able to help you.

The first step in asking for help can be making a list of people who are likely to agree and drawing up a list of tasks that have to be done. Then you can divide the tasks among the different helpers.

You should also think about organizations that may provide support, such as the Health and social services center of your community, the Centres locaux de services communautaires (CLSC) and the Centre de santé et de services sociaux (CSSSs, which now encompass CLSCs, long-term care facilities (CHSLDs) and hospital centres). The Quebec Ministry of Health and Social Services also provides services for family caregivers: caretaking (normal care activities when the live-in caregiver has to leave the house occasionally), respite (to provide some time off to make up for the stress and additional fatigue caused by caring for a disabled child or adult), assistance (to help family caregivers deal with unforeseen situations), support for daily tasks (various measures that relieve caregivers in their daily activities), psychosocial services (to help family caregivers adjust to the realities of supporting a person who is disabled, suffering a loss of autonomy or dealing with an episode of acute care), community services (offered by local authorities to support the development of individual assistance services and services for family caregivers)¹³.

You should also consult your local First Nations health and social services center to verify if these services are available. *The Guide d'accompagnement et d'information pour les aidants naturels* (accompanying guide and information for natural aids)*, published by the Centre-Ressources pour la Vie Autonome¹⁴ (Resource center for an autonomous life)* is available (in French only) at www.crvabsl.qc.ca; presents a three-step plan for learning to ask for help that may be useful to set up your request for support.

¹³ FNQLHSSC, 2006, *An Assessment of Continuing Care Requirements in First Nations and Inuit Communities*.

¹⁴ Cécily Trudeau and Isabelle Chassé, 2006, *Guide d'accompagnement et d'information pour les aidants naturels*, Centre-Ressources pour la Vie Autonome : Région Bas-Saint-Laurent.

* Free translation.

2.6 FACE THE TRIALS OF LIFE

It is important to acknowledge that sooner or later you may have to face major changes, losses or the death of the person you are caring for. It is also possible that you will have to be there to provide support as the person you are caring for experiences a loss. Even though these events are common, they are generally difficult to face. They propel us into a process of grieving that can demand a lot of inner strength.

Grieving is the set of reactions caused by a major emotional loss and, at the same time, the psychological process by which the grieving person detaches from the lost object of affection¹⁵. The grieving person is in mourning. Grieving can be triggered by different types of loss: loss of physical or intellectual capacity, being forced to quit a job, moving, or the institutionalization or death of a loved one.

There is no miracle formula for avoiding or curtailing the grieving process. It is a matter of time. The length of the grieving process depends on the individual and the loss, but understanding it can help people move on. Support from family and friends is also a very valuable source of strength when you are grieving.

You should understand that while every grieving process is unique, most people go through the same stages of grief:

1. Shock

The occurrence of the loss boils you over. You lose your sense of reality and you can't believe that what has happened to you is real. You may be overwhelmed by strong emotions or, on the contrary, remain untouched, with no reaction. You may even deny what has happened. All of these reactions are normal. This is the beginning of the grieving process.

¹⁵ Roger Régnier and Line Saint-Pierre, 2000, *Quand le deuil survient : 80 questions et réponses*, Éditions Sciences et Cultures inc., Montréal.

2. Destabilization or disorganization

You gradually come to understand that the loss is real. You are aware of the consequences and changes the loss will create in your life. You experience emotions such as anxiety, fear, anger, sadness, regret or guilt. You reminisce about what it was like before the loss occurred. You feel you will never get over it. This phase may be shorter or longer, depending on the type of loss, but it is essential for the grieving process, even though it is often painful and difficult.

3. Adjustment

Then your emotions start to become less intense. You begin to adjust to your new reality. The pain is less severe. Little by little, you become your old self or redefine your identity. You adjust and you detach. You start to regain your inner balance.

4. Recovery

The grieving process takes time – more or less, depending on the extent of the loss. It is very common to experience a lack of energy, low morale or mood swings during this time. Coddle yourself a little: rest, take it easy, and surround yourself with people you love who make you feel good. They will help you get through your grief and regain your energy.

When you take care of someone who is living with a loss of autonomy, your relationship with them will, by definition, be very intimate. Emotions are sometimes intense and may lead the people involved to do or say things that could be seen as manipulation, violence, abuse or neglect. It is important to realize that these situations may be instigated by family caregivers, other people in the family or support network or the cared-for person. As a family caregiver, you must be vigilant about your own behaviour and the behaviour of all the other people involved.

Having a good understanding of abuse is important. There are different types of abuse related to different victims (women, seniors, children, etc.). The Violence Info organization defines conjugal violence as attitudes, words and/or actions deliberately and repeatedly directed by a man toward his spouse that threaten her or her freedom. Violence is used as a way to dominate the spouse, to affirm his power over her and to make her feel anxious, afraid or even terrified. Abuse toward seniors is defined as any direct or indirect action intended to damage a person or harm their physical or psychological integrity, their possessions or their sense of identity, dignity and self-worth. It may also consist of neglecting to do something that is essential for their well-being or security. Finally, in terms of children, Violence Info indicates that children are often the first and only witnesses of conjugal violence between their parents. Children may be directly exposed to conjugal violence (be present when it occurs, hear violent words and see violent actions, see one parent strike the other, be used in violent strategies by the aggressor, etc.). Children may also be exposed indirectly to conjugal violence (perceive the distress of the victim, see the repercussions, live in tension, fear and insecurity, not receive the care and support they need). Children may also be involved in violent incidents in one way or another. They have to choose how they will react to each instance of violence: they may try to mediate, rescue their mother or distract the aggressor, take care of their brothers and sisters, or find outside help. They may also decide to do nothing and simply wait for the violent incident to end¹⁶.

In other words, violence or abuse takes many different forms. According to Violence Info, it may be subtle or overt. A single situation may involve different types of abuse. Abuse can be divided into eight categories: psychological, economic, physical, sexual, violation of rights, neglect, relational abuse and verbal abuse..

¹⁶ www.violenceinfo.com

3.1 PSYCHOLOGICAL ABUSE

Psychological abuse harms, hurts or distresses through the use of words, yelling, attitudes or actions. The aggressor may use different means to injure or frighten the victim, or make the victim feel guilty, in order to meet his or her own needs.

Here are a few examples:

- They treat me like a child or denigrate my abilities.
- They make decisions for me without considering what I want.
- They keep away from me, ignore me or deny me affection.
- They threaten to deny me visits or contact from people I love.
- Etc.

3.2 ECONOMIC ABUSE

Economic abuse is related to attempts to take the victim's money or assets. To achieve these ends, the aggressor may use manipulation, pressure or threats. Financial abuse also includes requests for money that the victim feels obliged to agree to. It may also include controlling the victim's cash flows. This type of abuse opens the door to other types of abuse such as psychological or physical abuse.

Here are a few examples:

- They force me to give them money, co-sign a loan or turn over assets.
- They force me to sign a power of attorney, change my will, or sell my property or house.
- They steal my money, my cheques, my pension or my personal belongings.
- They make me pay exorbitant prices for goods or services.
- Etc.

3.3 PHYSICAL ABUSE

Physical abuse means any action that harms the victim's physical integrity. It includes a range of actions from physical constraint to physical mistreatment. It may be carried out indirectly on objects or animals or directly on the person through threats or real assault.

Here are a few examples:

- They pinch, hit, push me or throw things at me.

- They force me to stay in my room.
- They mistreat a pet I love to make me suffer.
- They force me to take medication in an inappropriate way.

3.4 SEXUAL ABUSE

Sexual abuse consists of imposing sexual activity by force, manipulation or threat. It may occur through verbal aggression, suggestive behaviour, failure to respect privacy, unwanted fondling, etc.

Here are a few examples:

- They fondle me or assault me sexually.
- They make degrading comments about my physical appearance.
- They touch me inappropriately when they are washing or wiping me.
- They do not respect my privacy or disregard my modesty.
- Etc.

3.5 VIOLATION OF RIGHTS

Violation of rights includes actions, comments or attitudes that prevent a person from exercising control over their own life or making decisions about their life. The victim's opinions, wishes and choices are ignored.

Here are a few examples:

- They force me to live in an institution (institutionalization).
- They open my mail without my consent.
- They refuse to allow me to practise my religion or spirituality.
- Etc.

3.6 NEGLECT

Neglect consists of depriving a person of their basic needs, such as being fed and dressed, receiving appropriate personal care or medication, feeling safe, etc. This type of abuse may significantly undermine the victim's physical and psychological health.

Neglect may be active or passive:

- Passive neglect is when the aggressor unknowingly fails to meet the victim's physical or psychological needs.
- Active neglect is when the aggressor deliberately refuses to meet the victim's physical or psychological needs. The aggressor may deliberately fail to meet commitments by not providing the victim with access to available resources.

Here are a few examples:

- They don't provide me with a safe, warm and comfortable place to live.
- They don't offer appropriate health and personal care.
- They don't give me appropriate or sufficient food.
- They don't give me clean clothes or clothes that are suitable for the climatic conditions.
- Etc.

3.7 RELATIONAL ABUSE AND VERBAL ABUSE

Relational abuse most often occurs in couple relationships. It can be defined as disparaging and/or disdainful attitudes toward the victim's family and social network. It may also restrict or completely curtail contact with various networks (family, social, professional). It may entail geographic distancing or simply limiting the victim's means of movement.

The same is true of verbal abuse, which takes the form of yelling, insults, threats, intimidation, blackmail or changes in tone of voice. This is the verbal expression of the aggressor's authority over the victim.

It is important to point out that not all helping relationships lead to abuse. On the contrary, many helping relationships are based on mutual respect and deep, reciprocal love. But it is important to be vigilant about the possibility of violent behaviour on the part of the cared-for person, the family and support network, or the caregiver.

4 WHAT ABOUT DRUGS, MEDICATION AND ALCOHOL?

When you are giving a lot of your time and energy and facing the real risk of overwork and over-exhaustion, it is possible that you will look for ways to reduce the effects of fatigue and suffering. You may turn to prescription or over-the-counter drugs, alcohol, or soft or hard drugs.

While the occasional pill, beer or joint may help you de-stress, you should be aware that you are starting down a slippery slope. In the short term, the calming effects of these substances are attractive. But over the longer term, or when your consumption increases, the risk to your own physical and psychological health can be very real.

Prescription medication, such as anti-depressants, anti-anxiety drugs and sleeping pills, when used appropriately, can provide important help for real needs. But when taken incorrectly or without a doctor's supervision, they can cause unexpected problems over the medium or long term. You may experience serious side-effects, and some of these drugs can even be addictive. Different types of medication can also interact inside your body and cause serious health problems. That's why it is important that all medication taken by the caregiver and the cared-for person be supervised by a health care professional.

The same principle applies to alcohol and other drugs. A little bit of alcohol usually isn't problematic, but regular consumption of large amounts of alcohol has a serious effect on the body and mind. It affects your mood, coordination, and concentration¹⁷. It causes confusion, forgetfulness, depression, fatigue, trembling and lack of concentration in addition to real physical damage. In our society it is easy to get alcohol and it is generally socially acceptable to "knock a few back." That is why you must be doubly aware.

Drugs tend to be more hidden. In many communities, however, drugs are a growing problem that is becoming difficult to control. People have easy access to all sorts of soft and hard drugs. The physical and psychological effects of these drugs are just as serious as the effects of prescription drugs and alcohol. Violent behaviour is also likely to increase after consuming these substances, and this is another reason for increased vigilance.

¹⁷ Regroupement des aidantes et aidants naturel(le)s de Montréal, 1997.

4

WHAT ABOUT DRUGS, MEDICATION AND ALCOHOL? (CONT'D)

The best way to avoid the traps of substance abuse is to take good care of yourself, making sure you take time off regularly to do activities that refresh and energize you. It is also important to stay in contact with your friends so you have the opportunity to take a break from the helping role you play so often. These people can shake things up for you a little so you go back to your role as caregiver with a fresh outlook and renewed energy.

[http:// thingsarebetter.ca](http://thingsarebetter.ca)

You have made your decision: you are aware of the challenges of being a family caregiver but you also know about the immense benefits it can bring you. Rest assured that there are lots of resources to turn to for support in your new role. It's up to you to use them. Each of these resources has its own area of specialization and they're all there to help people like you. They will also help you establish a help network that you can turn to when you feel worn out and exhausted.

Just remember one thing: in order for people to meet your needs and help you meet those of the person you are caring for, you have to speak out and you have to ask!

The resources listed below are general resources. In every region there are local resources that can provide you with information or guidance depending on your needs. The Centres locaux de services communautaires (CLSC), the Centre de santé et de services sociaux (CSSSSs, which now encompass CLSCs, long-term care facilities (CHSLDs) and hospital centres) and the Health and Social service center of your community are places you can go for information. Don't hesitate to call them.

5.1 Resources for natural caregivers

- This Day is for Me: Caring for the Caregivers, The J.W. McConnell Family Foundation,
[www.fondationmccconnell.ca/utilisateur/documents/EN/Initiatives/Care Renewal/This_day_is_for_me.pdf](http://www.fondationmccconnell.ca/utilisateur/documents/EN/Initiatives/Care%20Renewal/This_day_is_for_me.pdf)
- Canadian Caregiver Coalition
Toll-free: 1 888 866-2273
Email: info@ccc-ccan.ca
Website: www.ccc-ccan.ca
- Hints for Caregivers
Government of New Brunswick, Family and Community Services
www.gnb.ca/0017/Seniors/hints-e.asp
- Guide d'accompagnement et d'information pour les aidants naturels (French only)
Centre-Ressources pour la Vie Autonome : Région Bas Saint-Laurent Toll-free: 1 800 301-2210
www.crvabsl.qc.ca

Regroupement des aidantes et des aidants naturels de Montréal

- La Boussole, Pour ne pas la perdre quand on s'occupe d'un proche, Guide des droits, des services et des ressources
- L'entourage, Cahier d'information et de sensibilisation
- Roue de secours, Document de soutien pour les aidantes

<http://perso.b2b2c.ca/raanm>

- Human Resources and Skills Development Canada
www.hrsdc.gc.ca/eng/cs/comm/sd/caregivers.shtml
- Caring, Coping and not Collapsing: Eldercare Survival Tips
Women's Health Matters
www.womenshealthmatters.ca/resources/show_res.cfm?ID=4211
- Canada Health Infoway
www.infoway-inforoute.ca
- La politique de soutien à domicile : Chez soi le premier choix (French only)
Ministère de la santé et des services sociaux
<http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2002/02-704-01.pdf>
- Caring, Coping and not Collapsing: Eldercare Survival Tips
Women's Health Matters
www.womenshealthmatters.ca/resources/show_res.cfm?ID=4211
- Multiple Sclerosis Society of Canada
www.mssociety.ca/qc/pdf/services/articlesSPQC_proches_aidants/extrait_dec05_aidants ANG.

5.2 Resources for seniors

- Avis sur l'état de situation des proches aidants auprès des personnes âgées en perte d'autonomie (French only)
Conseil des aînés
<http://collections.banq.qc.ca/ark:/52327/bs65912>
- Province of Manitoba Canada
www.gov.mb.ca/shas/resourcesforseniors/

Canadian Mental Health Association

- Supporting Seniors' Mental Health through Home Care: A Policy Guide and A Guide for Home Care Staff
www.cmha.ca/data/1/rec_docs/158_smhhc_polguide.pdf
- Aging Parents
[www.cmha.ca/bins/content_page.asp?cid=2-70-73&lang=1,](http://www.cmha.ca/bins/content_page.asp?cid=2-70-73&lang=1)
- Government of Canada
www.seniors.gc.ca

5.3 Resources for people with disabilities

- Persons with Disabilities Online
Toll-free service: 1-800-269-9607
www.pwd-online.ca
- Office des personnes handicapées du Québec (French only)
www.ophq.gouv.qc.ca

5.4 Resources on violence

- Public Health Agency of Canada,
(National Clearinghouse on Family Violence)
www.phac-aspc.gc.ca/ncfv-cnivf
- Violence Info (French only)
www.violenceinfo.com

5.5 Resources on Alzheimer's

- Alzheimer Society of Canada
Toll-free: 1-800-616-8816 (Canada only)
Email: info@alzheimer.ca
Website: www.alzheimer.ca

5.6 Resources on cancer

- Canadian Cancer Society
www.cancer.ca
- Fondation québécoise du cancer (French only)
www.fqc.qc.ca

5.7 Palliative care and end-of-life resources

- A Provincial Framework for End-of-Life Care
British Columbia Ministry of Health
<http://www.health.gov.bc.ca/library/publications/year/2006/framework.pdf>
- Canadian Hospice Palliative Care Association
Toll-free: 1-800-668-2785 / Palliative care information line:
1-877- 203-4636
Email: info@acsp.net
www.chpca.net/home.htm

CONCLUSION

You understand now that natural caregivers take on a number of roles: citizen, family caregiver, health and social services client, and partner of professionals. Being a family caregiver goes far beyond simply carrying out a series of tasks for someone who can no longer take care of themselves. It is a close relationship with the individual that demands time and personal investment.

To do your best as a family caregiver, it is important to develop your self-esteem, be assertive, learn how to recognize the signs of burn-out, ask for help and be prepared to face the trials of life. It may also be important to be aware of the different types of abuse in order to keep a sharp eye open for violent behaviour. Drug, prescription drug and alcohol abuse are other risks you should be wary of.

There is a wide array of resources to support you in the assistance you are providing to your loved one. Do not hesitate to call on these resources – they can be a great help in a time of need.

Remember that the role you are taking on is very gratifying, but that it can also be demanding. It is essential for you to take the time to refresh and renew your spirits. That is why we have provided you with a checklist where you can write down all the important information about the person you are taking care of. This checklist will be very useful for the person who takes over for you while you get some respite from your caregiving responsibilities.

In closing, we want to reiterate that taking care of someone you love entails its own share of challenges, problems and discouragement, but many people who have lived this experience speak of it as a positive, intense and profound journey. Being a family caregiver gives you the opportunity to create a new relationship with someone you love, to return love you have received, to develop new skills and knowledge, and to create memories. It is an experience that can bring you feelings of accomplishment and compassion, the joy of living in the moment, and a deep appreciation of life.

We wish you a wonderful experience as a family caregiver.

I HAVE THE RIGHT:

- 1 To take care of myself. This is not an act of selfishness. It will give me the capability of better taking care of my relative.
- 2 To seek help from others even though my relative may object. I recognize the limits of my own endurance and strength
- 3 To maintain facets of my own life that does 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 the same things just for myself.
- 4 To get angry, be depressed, and express other difficult feelings occasionally.
- 5 To reject any attempt by relative (either conscious or unconscious to manipulate me through guilt, anger, or depression.
- 6 To receive consideration, affection, forgiveness, and acceptance for what I do from my loved one for as long as I offer the qualities in return.
- 7 To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.
- 8 To protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.
- 9 To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.

¹⁹ Inuit Tapiriit Kanatami, 2006, *National Caregivers Strategy - Draft Final Report*.

ANNEX B

CHECKLIST: AN IMPORTANT TOOL

Now you know how important it is for family caregivers to take some time for themselves. To help you maintain your peace of mind when you do take time off, this section contains a checklist where you can write down information about the person you are caring for. This list will be used by the person who takes over for you while you take a break to refresh your mind and your body. The list can also be used as a support tool during visits by various health care professionals.

It is important for you to fill it out and keep it up to date. Use a pencil to make it easier to update.

You'll see that the checklist offers a number of other benefits, such as providing an overview of the situation, outlining the scope of the task, raising awareness of the responsibilities involved for the cared-for person and your other family members, serving as a springboard for discussions and negotiations, and sharing tasks¹⁸ that become too demanding for you to handle alone.

18 Regroupement des aidantes et des aidants naturel-le-s de Montréal, 1996, *L'entourage, Cahier d'information et de sensibilisation*.

CAREGIVER CHECKLIST

1. General information

First and last name of the cared-for person :

Date of birth : _____

Social insurance number : _____

Band number : _____

Health care number : _____

2. Health notes

Health problems : _____

Medication to take :

MEDICATION	DOSAGE	WITH FOOD	MORNING	NOON	NIGHT	SIDE EFFECTS	OTHER INFORMATION

Monitor, because patient does not always take medication as planned

Place to get the medications

Medication is kept here :

Pharmacist : _____

Telephone number : _____

Other care to be provided

CAREGIVER CHECKLIST

3. Specific needs

Glasses Other

Hearing aid Other

Cane Walker Other

Has trouble recognizing places People Date Other

Can't go alone Lives alone Other

Run away Other

Does not remember what happened yesterday Last month
Last year Other

Has trouble understanding instructions Other

Tends to be sweet-tempered Passive Aggressive Other

Uses sanitary napkins Diapers Other

Needs reminder to go to the toilet Other

Needs help getting dressed/undressed Eating Moving around
Getting up/going to bed Using the toilet Other

Personal hygiene : Needs help taking a bath Washing hair
Brushing hair Hand and foot care Teeth and denture care
Using medicated cream or lotion Other

Other useful information :

CAREGIVER CHECKLIST

5. In case of emergency

Doctor : _____

Phone : _____

Contact person : _____

Phone : _____

Reliable neighbour : _____

Phone : _____

Info-santé : _____

Hospital centre : _____

Police : _____

Medical clinic : _____

Health centre : _____

Fire : _____

CLSC : _____

The first aid kit is kept here : _____

Other useful information : _____



THIS DOCUMENT WAS CREATED FOR NATURAL CAREGIVERS, THEIR FAMILIES AND THEIR SUPPORT NETWORK, TO PROVIDE INFORMATION ABOUT THE VARIOUS ASPECTS OF THEIR ROLE. IT WAS ALSO DESIGNED TO HELP PEOPLE MAKE DECISIONS THEY WILL BE CONFRONTED WITH AS THEY EMBARK ON THE JOURNEY OF GIVING CARE TO SOMEONE WHO DEPENDS ON THEIR HELP.



CSSPNQL / FNQLHSSC
250, Place Chef Michel Laveau, local 102
Wendake (Québec) G0A 4V0
Phone : (418) 842-1540 Fax: (418) 842-7045
Website : www.cssspnql.com