

Survival Guide

Burnout prevention

The challenge of being a caregiver



Regroupement
proches-aidants
Rouyn-Noranda

Survival Guide



The challenge of
being a caregiver

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Printing: Impression Plus

Rouyn-Noranda 2004 & 2012

This guide was made possible with a generous contribution from the Secretariat aux aînés of the Ministry of Health and Social Services.

Acknowledgements

First of all, our sincere thanks go out to the committee members of the *Regroupement proches-aidants Rouyn-Noranda*, for without them, this guide would not have been possible. Their cooperation and devotion was motivating and inspiring.

We also wish to thank M. Jacques Mercier, community worker at the CSSS-RN, for his support in developing this guide.

Finally, we thank all the members of the various community organizations who accepted to share their experiences during a group meeting held on January 22nd, 2004.

Table of Contents

FORWARD

INTRODUCTION

PART 1: BEING A CAREGIVER 12

A. We, as caregivers 13

B. The day we became a caregiver 14

C. Being a caregiver is rewarding 15

D. Being a caregiver is demanding 15

PART 2: WHEN IT BECOMES DIFFICULT 16

A. The demands 17

 1. Work overload 17

 2. Worry 17

 3. Role conflicts 18

 4. Serious restrictions 18

 5. Communication problems 19

B. The stress 19

 1. Denial 19

 2. Anger 20

 3. Social isolation 20

 4. Loneliness 20

 5. Exhaustion 21

 6. Sleeplessness 21

 7. Emotional reactions 21

 8. Anxiety 22

 9. Depression 22

 10. Lack of concentration 22

 11. Health problems 23

C. Guilt 23

D. Daily losses 25

PART 3: AT PEACE WITH MY ROLE AS CAREGIVER 26

PART 4: WHEN THE CARE RECIPIENT IS NO LONGER AROUND 34

PART 5: SHARING WITH PEERS 39

A. The Regroupement proches-aidants Rouyn-Noranda 40

B. Its objectives 40

PART 6: BEING CONSIDERED A PARTNER RATHER THAN A RESOURCE 43

PART 7: FAMILY CONTRACT 46

PART 8: REFERENCE BOOK 49

CONCLUSION 57

BIBLIOGRAPHY 58

Forward

This document serves as a survival guide for family members who are caring for a severely ill or disabled loved one. Is it not questionable why we must caution the family of a sick person so that they do not fall under the emotional and physical burden caused by the support that they offer? Yet, we are told that it is normal, albeit “natural” to help our family! So why a survival guide?

Twenty years ago, when I first studied the impact of social policies on women, I discovered what was referred to at that time as the family caregiver. I asked myself: if helping family is something normal and natural as policies and governmental discourse would suggest, why do we need to invent a term like family caregiver? Why not just identify them as what they are – spouse, daughter, son, friend or friends?

Actually, the creation of this term announces an important change in expectations towards families and practices towards them. So, for over 20 years, in my research, I have tried to understand why the term was created and what it is hiding. I have since discovered two important aspects concerning it. First of all, I learned that the tasks carried out by someone who is caring for a loved one is more than just simple assistance. Whether it is to offer moral or psychological support, to manage crisis situations or disturbing behaviours, to cut up food, change adult diapers, manage staff, fight for services to leave work to go for a medical appointment, to change bandages or accompany a loved one to appointments, what caregivers provide is considered work.

It becomes more complex since it is carried out with emotional ties connected to daily living. Also, family caregivers provide 80% of the care needed by the sick or disabled member and that the value of their service, though invaluable, is worth thousands of dollars according to the Quebec Auditor General (2004).

I also learned that there is nothing “natural” in having to assume the role of caregiver. During my studies and discussions with caregivers, I have come to the conclusion that what is expected of these individuals surpassed what we should expect from a family member or friend. Family caregivers have become psychologists, nurses, attendants, occupational therapists, case managers. So what is natural when a daughter has to change the adult diaper of her father? When a mother is the only person to help her adult child suffering from head trauma to deal with anguish and loss? When an 85 year old spouse with osteoporosis must chase after her husband affected with dementia who is running away? When a husband must administer morphine to his wife to control pain due to cancer? When qualifying these realities as “normal” we trivialize the efforts that are put into care and assistance; we consider them as simply providing care for a family member, as being something simple, spontaneous that does not require special conditions or abilities. Now, the realities, as explained by the countless number of caregivers, are totally different.

Despite this, it is common to believe and expect that it is normal that family members will care for their sick family members. It is said that families have always cared for family members whether healthy or sick.

But beware! We cannot compare today’s reality to that of the past without putting everything into context. The people we care for at home now would not have survived fifty years ago.

Our era is unique because people are living longer despite the many debilitating and chronic diseases. When did we take care of sick adults longer than we care for children, like we do today? Is this normal and natural? Is it not due to social changes created by technical and pharmaceutical developments for which we must find collective answers?

We must acknowledge that when we start caring for a loved one, we will never know where it will lead us. We do not know what will be expected of us after one year, five years, twenty years... And, if at the beginning we can offer this help because of our love for the person, our recognition or affection and with time, it can become an obligation or a task carried out because of guilt rather than by choice. Also, though we want to help a loved one, we can end up caring for them, often on a full time basis because of a lack of appropriate services whether they are provided by the family, the community or a public organization.

Unfortunately, the general conception is that family care will be lovingly provided by those who are closely related without question. Consequently, this belief makes it difficult for caregivers like yourselves to establish boundaries, to question the reality of taking on such a task that has become very demanding which exceeds what is normally expected from a loved one. This justifies why a document such as this was developed.

As described in their manifesto, the Regroupement des aidantes et aidants naturel(le)s de Montréal states:

«They call us ‘family caregivers’ which often hides the fact that we are mostly women, sometimes men, who are obligated to devote our time and energy to help a sick or incapacitated loved one because of a lack of available resources.

We want to change this situation. Who we really are, are spouses, daughters, sons...

As caregivers, we do not want to neglect our own mental and physical wellbeing.»

To reclaim our status as spouses, daughters and sons, we must first acknowledge that we have become caregivers. This acceptance can allow us to question our role and to also self-identify within the caregiver group so that we can share this uncertainty with society in general.

It is with great enthusiasm that I present this guide as a step in the right direction. I hope that it will help clarify the role of the «family caregivers».

Nancy Guberman

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April 2004

Introduction

This guide was designed for you, the family caregiver, to help deal with the risks involved when caring for a loved one who is losing their independence. It will allow you, if only while you are reading, to take a break and to take care of you.

First of all, it will help you reflect on your experience as a family caregiver. This first step will help you define a realistic portrait of your life with consideration to the different facets that are an integral part of your role.

Afterwards, we will suggest different strategies to prevent or remedy certain difficult situations by determining your needs and limitations. Some practical tools will help you to channel your strength towards a better feeling of wellbeing.

We will present the advantages of sharing with our peers. In this sense, we will present the objectives of the Regroupement proches-aidants Rouyn-Noranda.

We have also permitted ourselves to sound the alarm to the health and social services network, so that they consider family caregivers as a partner rather than a resource.

Finally, a family contract and reference book are in appendix to help you with your role as family caregiver.

Enjoy the read!

To obtain a full
copy of the Sur-
vival Guide for
just 10\$, please
contact the
Regroupement

Conclusion

In this guide, we have described the realities faced by a family caregiver. Ideas and strategies have been suggested to prevent difficult situations that are inherent with your role and how to solve them. We have discussed the topics of regrouping and being heard in order to improve your quality of life.

This document was not conceived to dramatize the situation of family caregivers, but to offer assistance as a tool for everyone who is caring for a loved one.

Finally, we hope that this guide has provided information and ways to do things. We must remember that one day we too might need the help of a family member.

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If you need information, support,
or someone to listen, the
Regroupement is there for you.

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