

Reference document

Supporting a sick loved one



Table of contents

Introduction	2
Support	2
Current state of affairs	2
Caregiver support	3
Financial and material support	3
Refusing treatment	3
Conclusion	4
References	4

Introduction

Living with someone who is seriously ill, disabled or nearing the end of their life is definitely a painful and distressing ordeal, both personally and professionally. In such difficult times, some people choose to or are forced to become caregivers. Accompanying a sick person involves major responsibilities, which is why it is important to consult the appropriate resources and make sure to receive proper guidance.

Support

The caregiver, also called an informal caregiver, natural caregiver, substitute caregiver, family caregiver, live-in caregiver or non-professional caregiver, is an indispensable member of society. The caregiver supports the person experiencing a loss of autonomy, sometimes with a significantly lower quality of life or even the possibility of death. Supporting, caring for and alleviating the suffering of the sick person are thus among the caregiver's objectives. But accompanying a seriously ill person is demanding, and it can be easy to get overwhelmed by the responsibilities that it entails. For example, what should a caregiver say and not say to a seriously ill person whose condition is worsening or who is losing their physical, psychological or cognitive autonomy? How does a one give a sense of security to a vulnerable person who may feel at the mercy of those taking care of them?

When we care for a seriously ill loved one for physical or mental health reasons, be it following a car accident, an industrial accident, the discovery of a degenerative disease or cancer, or for any other reason, several questions may be raised about the following subjects:

- The illness's symptoms and after-effects
- The treatment plan
- Pain management
- The prognosis for recovery
- Physical changes associated with a degenerative disease
- The daily hygiene care to provide
- Hospital or home care and services

- The technological adaptations needed to ensure the safety of the sick person and their loved ones
- Travel and transportation if mobility is reduced
- Communication between the medical team, the caregiver and loved ones
- Stress management
- Each person's rights and duties
- Respite and assistance services

Current state of affairs

According to Statistics Canada, the number of Canadians providing care to at least one loved one in 2012 was estimated to be more than 8 million. The care provided included transportation, meal preparation, bathing and dressing, as well as assistance with medical treatments.

The same study states that the most frequent kind of caregiving was assistance to parents for various conditions:

- Aging-related problems (28%)
- Cancer (11%)
- Heart disease (9%)
- Mental health problems (7%)
- Alzheimer's disease or dementia (6%)

However, the overall picture is slightly different for caregivers of spouses or children. In those cases, the different conditions are:

- Cancer (17%) for care of a spouse
- Mental health problems (depression, bipolar disorder and schizophrenia; 23%) for care of children

The study also shows that 48% of family caregivers have provided care to their own parents or their in-laws. Adult children are nearly four times more likely to take care of a parent than a parent-in-law, and two and a half times more likely to provide care to their mother than their father. The latter tendency may be due to the fact that elderly women often live longer than their spouses. They must therefore look to their children for assistance if they have aging-related health problems.

Caregiver support

The requirements of being a caregiver can be demanding and pose a risk to one's health. It is therefore recommended that the caregiver seek any necessary help. Medical and health care teams, volunteer and support associations, patients' associations, self-help groups, CSSSs and CLSCs may provide individual, family or community support to meet these needs. In the event of a sick person's death, their loved ones may continue to receive support to help them as they grieve.

Unfortunately, too often caregivers experience burnout for various reasons, such as:

- Wanting to solve and manage everything on their own
- Feeling like the only person who can and must do everything
- Not wanting to bother those around them
- Complying with the wishes of the sick person who does not want another person taking care of them

Given the high demands of such a role, caregivers must be able to set limits for themselves even before symptoms of fatigue are felt. It is also recommended that they take time for themselves and maintain a healthy lifestyle, with regular sleep and a balanced diet, to keep their energy up.

It is also important to ask the sick person what they want and seek the support of relatives and resources in the community to meet their needs as well as possible. Important matters must

also be considered according to the sick person's age, personal and religious values, functional abilities and medical restrictions and recommendations, in order to maintain the person's autonomy as much as possible.

Financial and material support

Financial issues can be a major source of worry for sick people, their loved ones and their caregivers. Fortunately, there are various assistance programs designed to help meet financial needs in these situations. For example, Employment Insurance provides compassionate care benefits to people who have to be away from work temporarily to provide care or support to a family member who is gravely ill. The Employment Insurance program can also provide support to sick people, pregnant women, parents who are caring for a newborn or adopted child, and parents who must provide care or support to their critically ill or injured child. Other kinds of support are also available; the necessary information can be obtained by contacting community social services.

Refusing treatment

Sometimes, a caregiver will be faced with someone who refuses to be treated. The issues of human rights and each person's values immediately come up: what can be done, and how can it be done diplomatically?

Although it is possible to hospitalize a person against their will under certain conditions, there are laws that need to be followed scrupulously. Furthermore, even if the intention is to ensure the person's safety and well-being, they may resent those close to them, putting their caregiver and loved ones in a heartbreaking situation. In cases like these, it is essential to seek the advice and services of a third party expert.

However, there are legal measures that can be taken to protect the sick person, their loved ones and their caregivers. These measures fall under different kinds of plans, depending on the specific situation and the province or territory of residence. Community social services should be contacted to obtain the necessary information and proper guidance.

Conclusion

In order to prevent additional difficulties from arising while acting as a caregiver, it is important to make sure, while you are healthy and in full control of your cognitive faculties, that all needs are covered in the event of serious illness. Putting your wishes and requests in writing, naming the people who will take care of you and discussing it with your loved ones are worthwhile measures to consider. Unfortunately, too often these actions are taken in emergency situations or when the person is in a very physically or psychologically vulnerable state, making the situation that much more difficult.

References

CANADIAN INSTITUTE FOR HEALTH INFORMATION. *Supporting Informal Caregivers—The Heart of Home Care*, Ottawa.

Canadian Mental Health Association: www.cmha.ca/mental_health/family-support-common-questions/#.WB1c2qYeZz8

Centre National de Ressources Soins Palliatifs/Service Canada/Canadian Institute for Health Information, 2010.

CURATEUR PUBLIC DU QUÉBEC. "Drawing up a mandate": www.curateur.gouv.qc.ca/cura/en/majeur/client/prevoyant/demarches.html

GOLAY RAMEL, Martine. *Les proches aidants : Aider un proche malade et/ou âgé*.

Publications du Québec. *A Close Relative or Friend Becomes Incapacitated—How Can You Protect Them?*

Publications du Québec. *In case of incapacity: the mandate*.