



# 12

## End of the Life Course Social Support, Public Policy, and Dying Well

### Chapter Overview

In this chapter, you will be exposed to a number of issues pertaining to end-of-life experiences. Special focus is given to elder care/caregiving from both family and policy perspectives. Informal and formal support are covered, as well as their interfaces.

Particular attention is devoted to three areas. The first is caregiver issues, especially caregiver burden and the role that formal services play in the continuum of care. The second is elder abuse, which is presented as a hidden social problem. The third deals with end-of-life issues related to dying well, including ethical issues, palliative care, bereavement, and rituals and ceremonies. The chapter finishes with a discussion of key public policy debates related to an aging population.

### Learning Objectives

By the end of this chapter, you will be able to do the following:

- Articulate and support an argument as to whether and to what extent the family versus the public or private sector should provide care to older adults living in the community.

- Detail the multiple ways in which caregiving responsibilities influence the work, family, and leisure life of caregiver.
- Write a short essay as to how an integrated continuum-of-care system can be designed to ensure that the assistance and services needed by older adults are delivered at the right time, in the right place (the home, community, or institution), and by the appropriate persons.
- Describe why, and in what form, elder abuse or neglect occurs within families, and prioritize the precipitating factors.
- Understand and defend how we, as individuals and as a society, ensure a “good” death with dignity and choice.

## Key Facts

- Globally, in the coming decades, there may be as many as two to four times the number of older persons needing care than there are people to provide care.
- More than two million Canadians provide informal care or support to an older adult who is a family member or a close friend.
- Most caregivers are between the ages of 45 and 64, and the most common care recipients are older parents or spouses.
- About 28 per cent of caregivers can be considered “sandwiched” between caregiving and childrearing, having at least one child under 18 living at home.
- In 2015, about one in six older adults aged 65 and over reported receiving some level of home-care services from private or public agencies.
- It is estimated that one in four elderly people around the world experience some form of abuse in their home. In Canada, it is estimated that approximately 7 per cent of older persons experience spousal abuse or neglect only, and is likely over 10 per cent for all sources of abuse.

## Key Terms

**Assisted suicide** The provision of drugs and/or advice so that a patient can end his or her own life. (p. 413)

**Elder abuse** A conscious or unconscious physical, psychological, or fraudulent act against a frail or dependent older person. This action may result in physical, psychological, or financial trauma for the older person. (p. 404)

**Elder neglect** The failure or refusal on the part of a caregiver to meet an older adult’s physical or psychological needs. (p. 405)

**Euthanasia** An active or passive action that is taken to end a life. (p. 413)

**Formal support** The provision of assistance and care by formal or voluntary associations in the private sector and by formal agencies in the public sector. (p. 385)

**Hospice movement** A philosophy that promotes “death with dignity” through the provision of care centres to assist those who are dying from a terminal illness, and to provide support to relatives and friends of the person who is dying. (p. 416)

**Informal support** The provision of care and assistance by members of the extended family, neighbours, and friends. This process may or may not involve an exchange of resources. (p. 388)

**Palliative care** A type of care that seeks to improve the quality of life for a dying person by relieving his or her physical pain and psychosocial discomfort. (p. 416)

**Respite care** A service available to caregivers that gives them relief from daily caregiving demands through a daily, weekly, or vacation break. Respite provides brief periods of temporary emotional, psychological, and social normality in a caregiver’s life. (p. 399)

**Self-abuse** The outcome of a lifestyle in which an individual consumes excessive amounts of alcohol or drugs or ignores normal safety or nutrition practices, thereby placing himself or herself at risk. (p. 405)

**Self-neglect** The failure of a person to provide himself or herself with the necessities for physical and mental health, including a safe environment. (p. 405)

## Study Questions

*See below for answers.*

1. Family support or “informal social support” is a growing issue for an aging population. What are the sources of social support, outcomes, costs, and stress related to caregiving in an aging society?
2. What is elder abuse? What effective strategies can be used to prevent abuse and neglect among the aging population?

## Additional Resources

### *Articles and Reports*

Fast, J., Keating, N., Lero, D., Eales, J., Duncan, K. (2013). [The economic costs of care to family/friend caregivers: A synthesis of findings.](#)

National Initiative for the Care of the Elderly. 2015. [The National Survey on the Mistreatment of Older Canadians: A Prevalence Study.](#)

### *Videos*

Employment and Social Development Canada. 2016. [Caregiver Readiness](#) (1:39 minutes)

Today, over 8 million Canadians are caregivers for someone they know. And this number is expected to increase with our aging population. At some point, you will likely need to care for someone you know by helping them with groceries, appointments, or finances. From a physical

disability, mental health challenge, to long term illness—a family member, a close friend or a neighbour might need your help. Now is the time to make a plan.

Acart. 2012. [It Is Time to Face Reality](#) (1:38 minutes)

This national campaign against elder abuse, created for Human Resources and Skills Development Canada, achieved some of the best awareness and social marketing results the Government of Canada has ever recorded.

Goldman, B. 2018. [One year after MAID: A husband talks about being the spouse left behind](#), White Coat, Black Art, CBC Radio. (26:29 minutes)

In our second show exploring the impact of Medical Assistance in Dying (MAID) we speak to Clifford Campbell. His wife Noreen was among the first to be approved for and to receive MAID. He tells Brian what it's like to be the witness to suffering, party to assisted death, and the spouse left behind. Listen to [Noreen's Story](#).

Kastner, K. 2013. [Exit Laughing](#), TEDxYorkU. (11:42 minutes)

In 2008, Kathy launched Ability4Life, a website dedicated to adult children who are caring for aging parents. This eventually led to a hospice and palliative medicine Twitter chat where she realized how little she knew about medical interventions at life's end; [BestEndings](#) is the curation of this journey and the resources she's found along the way.

### ***Websites***

Canadian Centre for Elder Law, [www.bcli.org/ccel](http://www.bcli.org/ccel)

Canadian Hospice and Palliative Care Association, [www.chpca.net](http://www.chpca.net)

Canadian Medical Association, Demand a Plan, [www.demandaplan.ca](http://www.demandaplan.ca)

Canadian Virtual Hospice, [www.virtualhospice.ca](http://www.virtualhospice.ca)

Carers Canada, [www.carerscanada.ca](http://www.carerscanada.ca)

## Study Questions—Answers

1. For older people, an informal support network has the potential to prevent or alleviate stress and to help them make decisions, live independently, and recuperate from an acute illness or adapt to a chronic illness. Supportive family, friends, and neighbours can enhance or maintain physical or mental health and contribute to higher levels of well-being and life satisfaction. Among older adults who live alone, isolation and loneliness can be alleviated by an informal network of supportive friends and acquaintances. But not all assistance is beneficial. Although the caregiver may have the best intentions, the recipient may see things quite differently. For example, older persons may resent the loss of privacy that results from increasing levels of personal care—they may feel they are being overprotected and losing personal control, and they may resent being treated like a child in a demeaning manner, especially if they are frail. If different formal-care workers visit the home, an older person may not trust them, may regard them as unwanted strangers in their home, or may view their work as unnecessary or shoddy. Moreover, if the level of interaction with caregivers fails to meet needs or expectations, or if a primary caregiver experiences a crucial life transition (a job promotion, failing health), an older person may feel neglected, deprived, and isolated. (pp. 388–394)
2. There is no single definition of elder abuse and neglect, although there is agreement that the major types of elder abuse include physical, psychological, financial, and sexual abuse. The World Health Organization has developed a commonly used definition: “a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person.” In general, three types of instruments have been used to measure or identify abuse or neglect: *interviews* with older people by professional care workers to identify victims; *classification schemes* to indicate types of abuse; and *survey instruments* with lists of abusive behaviour to identify incidents of abuse or attitudes around whether such behaviour is abusive and, if so, how prevalent it is. The Elder Abuse Survey Tool (EAST), designed by Stones and Bédard (2003), lists 96 behaviours that constitute mistreatment in a situation where a person lives with or is supervised by a person in a position of trust and 15 that might take place when older people live in an institution. (pp. 402–410)