

Caregivers and Caregiving

There are only four kinds of people in the world – those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers. (Rosalynn Carter).

“Invest in the human family. Invest in people. Build a little community of those you love and who love you. In the beginning of life, when we are infants, we need others to survive, right? And at the end of life, when you get to be like me, you need others to survive, right? Then Morrie’s voice drops to a whisper. “But here is the secret: in between we need each other as well.” (taken from “*Tuesdays with Morrie*” by Mitch Albom)

Defining Generic Key Terms and Concepts

Caregiver: The study, “Caregiving in the U.S”, funded by the MetLife foundation (April 2004), defined a care giver as someone who provides unpaid care to another who requires help with activities of daily living (ADLs) or instrumental activities of daily living (IADLs). A family/informal caregiver in Canada is defined as an individual who provides care and/or support to a family member, friend or neighbour who has a physical or mental disability, is chronically ill or is frail. As a result of a policy and a societal shift away from institutional care, more people are being cared for in their homes and communities. This is creating an increased demand for family caregiving. With over two million family/informal caregivers in Canada, caregivers play a critical role in the sustainability of the home and community care sector (Health Canada, 2007 website)

Domestic elder abuse: is the mistreatment of an older person by someone who has a special relationship with the elder (spouse, sibling, child, friend, or caregiver) in the older person’s home or in the home of the caregiver.

Institutional elder abuse: is the mistreatment of an older person who lives in a residential facility (e.g., a nursing home, foster home, group home, or board and care facility). Abusers are usually people who have a legal or contractual obligation (e.g., as paid caregivers, staff, or professionals) to provide the elder victim with care and protection.

Self-neglect: When the behaviour of the older adult themselves threatens their health or safety this situation is called self-neglect and includes such activities as refusing or failing to acquire adequate food, water, clothing, shelter, personal hygiene, medication, or safety precautions.

Respite care: Respite care is one form of caregiver assistance. It involves family members, professionals, or volunteers who come to care in the recipients’ homes to provide relief for the caregiver. Sometimes the care recipients can leave the home to attend day care programs for specified periods of time, which allows caregivers the opportunity to run errands or get away for

Age-Friendly Business®

Core Concepts, Definitions and Practice Questions

a while. Respite care varies in nature and in cost depending on what the recipient is capable of handling and who is providing the respite care. Respite care reduces the incidence of caregiver burnout and, over time, can allow the care recipient to stay at home longer.

Thought-provoking terms and questions—seek to understand these basic terms, concepts and directives during the course:

What is the difference between formal and informal caregivers and what is the difference between skilled caregivers and unskilled caregivers?

Formal caregivers are professional providers, whether through home care, or in an institutional setting. Informal care givers are family or friends, who are estimated to provide over 90% of caregiving in North America. Formal care givers are paid while informal caregivers generally are not compensated.

Skilled caregivers are professionals who require specific training to provide the type of care they do – for example a Licensed Practical Nurse, Geriatric psychologist, care aide, home care Nurse whereas a non-skilled caregiver may be someone who helps with housekeeping, companionship, making meals etc where no specific training or qualifications are required.

Family members in North America now are responsible for a very high percentage of caregiving. What are some of the results of caregiving for a family member?

Caregiving for a family member can result in:

- Financial stress: lost wages and retirement contributions, added cost to support care recipient
- Lost social benefits – missing out on socializing with friends and other hobbies, interests
- Physical stress – sleeplessness, fatigue, stomach disorders
- Emotional stress – anxiety, inappropriate laughing, crying, indecision, apathy, anger, depression (six times the national average)
- Behavioural stress – substance abuse, decreased personal hygiene, time off work, old family dynamics

Note: Caregivers can also gain a great sense of joy and satisfaction in helping their family member or friend giving them a sense of purpose and love in action. It can be a positive and transformational process for all.

Age-Friendly Business®

Core Concepts, Definitions and Practice Questions

As a PROFESSIONAL where would you advise a client to begin seeking information on and answers to caregiving and care concerns?

Elder Care is the entire network (maze) of both public and private professional services and residential facilities concerned with providing specialized care, therapy and support for older persons and their families. Some excellent sources of information are:

- The family physician is a good place to begin as he or she can do a medical assessment and direct the senior and family to appropriate specialists
- Best In Care/Parent Care Professional Program: a source of comprehensive and independent expert advice is available for a nominal fee to PROFESSIONAL's and can save you and your clients enormous time and money sourcing information on senior resources and facilities.
- The regional Community Health Authority and its resources
- Organizations that deal with specific disabling conditions – Heart and Stroke foundation, Alzheimer's society, etc. offer valuable information, contacts and resources
- Federal and Provincial government websites Health and Senior Services divisions have excellent resources and links available. (i.e. National Advisory Council on Aging)
- Friends, family or acquaintances that have gone through similar situations

Our aging population is considered a 'phenomenon' in North America, how has this trend evolved/what has caused it?

The trend is essentially due to a significant increase in longevity and a significant decrease in the birth rate.

What care-related services are in your community? Where can you advise your clients/others to go to find this information?

Community health services and community social services are the first place to start.

As a PROFESSIONAL, when you are meeting with a caregiver of a dementia parent, what health condition should you be watching for?

You should be looking for signs of depression, stress, fatigue or possible substance abuse.

Almost half (47%) of the care-help is with 'instrumental activities' (e.g. cooking, cleaning, meals, laundry, banking, transportation, bill paying...); the next largest need (46%) is for what type of activities?

The next largest need also represents a higher level of care needed with what are known as activities of daily living (ADL) dressing, toileting, bathing, transferring, feeding. A need for assistance with one or more of these may be due to cognitive impairment.

Age-Friendly Business[®]

Core Concepts, Definitions and Practice Questions

What two major health conditions are most strongly linked with the need to receive home care?

Cancer and stroke are the health conditions most closely linked with the need to receive home care followed closely by arthritis and heart disease.

In general, what do you know of violence against seniors?

It is under reported and if it is not interrupted or stopped, it will escalate.

Caregiver burnout is a problem—what tools/programs are available to help reduce this problem?

Respite care and adult day care programs as well as support programs for caregivers are very helpful. Ensuring the caregiver has regularly scheduled time off is also very important. Access to informal and professional emotional support and educational resources can be of significant benefit.

Additional Thought-Provoking Questions

1. Boundaries are also known as *psychological fences* because they define emotional limits. They delineate what is “in bounds” and what is “out of bounds”. In healthy relationships, boundaries act as operational parameters that outline how the caregiver/care recipient relationship works.

List some of the resources that can help caregivers with some of the caregiving load as well as help to prolong the senior’s ability to remain in the community.

- Education and support services located through general aging organizations or through disease specific organizations (e.g., Alzheimer’s Society)
- Home health Aids
- Care managers
- Neighbours
- Churches
- Volunteers
- Hospice care
- Respite care
- Adult day care or night care programs
- Delivered meals
- Housekeeping services
- Financial advisors
- Transportation services – (e.g., Handydart)
- Seniors Centres
- Personal emergency Response Systems

Caregivers say having someone to listen, help them organize their thinking, and reassure them is a valued service.

Age-Friendly Business®

Core Concepts, Definitions and Practice Questions

Review Questions

1. The three factors that have the greatest effect on caregivers' emotional stress, physical strain, and financial hardship due to caregiving include all of the following except:
 - A. Level of burden
 - B. Whether caregivers felt they had a choice in becoming a caregiver
 - C. Caregivers' health
 - D. Whether or not the caregiver is married

2. Three of these are signs of elder abuse, one is **NOT**, which one is not?
 - A. Untreated medical conditions or poor personal hygiene
 - B. Unexplained appearance of funds or valuable possessions
 - C. Abrupt changes in a will or other financial documents
 - D. Grossly inadequate housing



Age-Friendly Business® Core Concepts, Definitions and Practice Questions

Caregivers and Caregiving:

1. d
2. b