

Quality of Life

BACKGROUND

For each person, the definition of quality of life is different and deeply personal. One person may define quality of life as enjoying the beauty of a sunset. Another person may describe it as sharing a holiday celebration with family; worshipping at a church, synagogue or mosque; playing a game of bridge; washing a car; listening to music or solving a crossword puzzle. Each person has a unique standard of what has value and what gives quality to life.

In defining quality of life, many different factors may be considered, such as:

- the ability to think, make decisions and have control in one's daily life
- physical and mental health
- living arrangements
- social relationships
- religious beliefs and spirituality
- cultural values
- a sense of community
- financial and economic circumstances



THE ISSUES

For people living with dementia:

Influencing one's own quality of life: As dementia progresses, a person will lose many of the abilities considered important to quality of life. Some people think that quality of life is lost once a person is diagnosed with dementia. Others feel that quality of life can be maintained well into the dementia process.

People at the early stage of dementia usually know what gives them pleasure and contributes to their sense of well-being. They may seek help to adapt to changing abilities and participate in meaningful activities. However, if the person can no longer communicate or make choices and decisions, then caregivers, family members or healthcare providers will need to make decisions for them.

For caregivers:

Determining someone else's quality of life: Determining how another person would define quality of life is not easy, but it is extremely important. It is vital to avoid imposing one's own personal values and interpretation of quality of life on someone else. The abilities and interests of a person with dementia will change over time. However, every effort should be made, especially as their dementia progresses, to provide them with an optimum quality of life.

Effects of caregiving: Many caregivers can gain a sense of satisfaction and growth from caregiving but may have difficulty balancing their own needs and those of the person with dementia. The tasks and responsibilities of caring for a person with dementia can have positive and negative effects on the quality of life of caregivers. The degree to which their quality of life is affected may be influenced by:

- the nature (parent, spouse, friend, partner) and strength of the relationship between the person living with dementia and the caregiver

- the personalities of the person with dementia and the caregiver, and the ability of each to adapt to changes caused by dementia
- the psychological, physical, spiritual and financial resources of the caregiver
- other day-to-day roles and expectations, such as being an employee, parent, business person or volunteer
- the caregiver's location and place of residence, in relation to that of the person with dementia
- the opinions, views and demands of people outside the caregiving relationship
- a healthcare system that seems to be placing more responsibilities on caregivers while providing less and less support

Young children in the family may also find their own quality of life affected, as they may need support and attention that the caregiver and the person with dementia may be unable to give.

For healthcare providers:

Lack of understanding, training and human resources:

Some healthcare providers who provide care for people with dementia lack an understanding of the issues relating to quality of life. Consequently, they fail to implement preferred care strategies. Long-term care homes may also lack appropriate educational, human and financial resources to provide quality care for people with dementia.

PREFERRED CHOICES

Quality of life for people with dementia

Everyone involved in the lives of people with dementia should know or learn that, despite changes and loss of abilities, people with dementia are able to find pleasure and experience satisfaction. Dementia does not remove a person's ability to appreciate, respond to and experience feelings such as anger, fear, joy, love or sadness. Recognizing abilities, interests and life-long skills helps to maintain and enhance that person's quality of life.

Quality of life for caregivers

Caregivers must strike a balance between their own quality of life and the quality of life of the person they are caring for. If they are unable to do so, then those close to them should help them recognize this need for balance.

Care strategies for healthcare providers

Healthcare providers who provide care to people with dementia must recognize that they play a role in influencing the quality of life of both the person living with dementia and their caregiver. Professionals should try to devise care strategies that enhance the quality of life for both.

WHAT CAN BE DONE TO ENHANCE THE QUALITY OF LIFE OF PEOPLE WITH DEMENTIA?

People with dementia are individuals and need to be treated with respect, integrity, compassion and dignity, and with concern for their privacy and safety. People in the early stages of dementia may need support in finding opportunities to enhance their quality of life. As dementia progresses, preserving the quality of life of the person with dementia will require the provision of appropriate social and physical environments.

Some key elements to consider include:

- Learning about dementia, understanding how it progresses and knowing how to communicate with the person with dementia; for instance, learning how a particular person's facial expressions convey emotions such as joy and fear.
- Consulting the person with dementia to learn more about particular likes, dislikes and opinions; and, when the person is unable to communicate this, talking to someone close to the person.
- Knowing the person with dementia and being aware of people, activities and things that are known to give them pleasure.
- Providing the necessary support to preserve as much independence as possible.
- Building on the strengths and abilities of the person with dementia, and encouraging a sense of feeling useful and valued.
- Giving opportunities to make choices.
- Ensuring that overall health is monitored and assessed, and that appropriate treatments are given. A diagnosis of dementia does not automatically prevent the presence of other health concerns and diseases. Failure to treat other illnesses can worsen the symptoms of dementia.
- Providing living space that is safe, familiar and provides a sense of security, while allowing the maintenance of remaining abilities.
- Respecting the need for companionship, including physical intimacy. Relationships with family and friends should be fostered as much as possible.
- Providing care that responds to individual needs and focuses on abilities rather than losses.
- Acknowledging and recognizing that interests may change over time rather than trying to impose former values and expectations.
- Ensuring that all who provide care for people with dementia recognize that people with dementia are to be valued and should be treated as individuals.
- Recognizing that all actions and changes in behaviours of people with dementia are meaningful and reflect a desire to communicate something.
- Recognizing that the quality of life of the person with dementia is closely linked to the quality of life of their caregiver. As their dementia progresses, the connection between the two may become stronger.

WHAT CAN BE DONE TO ENHANCE THE QUALITY OF LIFE OF PEOPLE WHO PROVIDE CARE?

Strategies to enhance the caregiver's quality of life include:

- Learning about dementia, understanding how it progresses and learning how to communicate with people with dementia.
- Talking to close friends about one's needs, the needs of the person being cared for and where the two sets of needs conflict.
- Finding ongoing support from groups or from one-on-one relationships.
- Taking regular breaks from caregiving for a few hours, days or weeks, and finding activities that help one spend time away from caregiving responsibilities and tasks.
- Recognizing the signs of stress and developing ways to deal with them.
- Taking satisfaction in the work one is doing to provide quality care.
- Learning to ask for and accept help.
- Making sure the doctor knows that one is caring for a person living with dementia, to ensure that one's health is monitored and appropriate treatments obtained.
- Becoming aware of one's own feelings and reactions to stress. Taking care of one's needs throughout the course of the dementia journey.
- Planning for change and recognizing that there may be difficult decisions ahead.

- Acknowledging the need for companionship and physical intimacy. Relationships with family and friends should be fostered as much as possible.
- Listing the negative and positive aspects of caregiving, and seeking help from others to increase the positives and decrease the negatives.
- Learning about available community resources by contacting one's local Alzheimer Society.

IN CLOSING...

The quality of life of the person with dementia must be a central focus of care. It is vital that those providing care respond to that person's needs, wishes and values. The ultimate goal of care must be to provide a sense of well-being for that person.

At the same time, it must be recognized that the quality of life of the caregiver can be as important as that of the person living with dementia. When conflicts arise, communication, information, self-awareness, support and understanding can help caregivers enhance their quality of life.

RESOURCES:

From the Alzheimer Society of Canada:

First steps for families

Reducing caregiver stress

Guidelines for care: Person-centred care of people with dementia living in care homes.

Available at alzheimer.ca/library

Alzheimer Society

Alzheimer Society of Canada

20 Eglinton Avenue West, 16th Floor, Toronto, Ontario M4R 1K8

National office: 1-800-616-8816 Information and Referrals: 1-855-705-4636 (INFO)

E-mail: info@alzheimer.ca Website: alzheimer.ca

Facebook: facebook.com/AlzheimerCanada Twitter: twitter.com/AlzCanada