

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 with Alzheimer's disease or other dementias:

Influencing one's own quality of life: As the disease 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 disease process.

People at the early stage of the disease 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 health-care providers will need to make them.

For family members and 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 someone with dementia will change over time. However, every effort should be made, especially as the disease progresses, to provide an optimum quality of life for the person.

Effects of caregiving: Many caregivers derive a sense of satisfaction and growth from caregiving but may have difficulty balancing their own needs and those of the person with the disease. The tasks and responsibilities of caring for someone with dementia can have positive and negative effects on the quality of life of family members and 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 with the disease and the caregiver;

- the personalities of the person with dementia and the caregiver, and the ability of each to adapt to changes caused by the disease;
- 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, volunteer;
- the caregiver's location & place of residence, in relation to that of the person;
- the opinions, views and demands of people outside the caregiving relationship;
- a health-care system that seems to be placing more responsibilities on caregivers while providing less and less support.

Young children in a caregiver's family may find their own quality of life affected, as they may need support and attention that the caregiver is unable to give.

For health-care professionals:

Lack of understanding, training and human resources: Some health-care professionals who provide care for people with Alzheimer's disease and other dementias 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

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

Quality of life for family members and caregivers

Family members and 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 health-care providers

Health-care 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 with the disease and the 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 ALZHEIMER'S DISEASE OR OTHER DEMENTIAS?

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

Some key elements to consider include:

- Learning about the disease, understanding how it progresses, and knowing how to communicate with the person with the disease; for instance, learning how a particular person's facial expressions convey emotions such as joy and fear.
- Consulting the person 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 who can.
- Knowing the person and being aware of people, activities and things that are known to give pleasure to the person.
- Providing the necessary support to preserve as much independence as possible.
- Building on the person's strengths and abilities, and encouraging a sense of feeling useful & valued.
- Giving the person opportunities to make choices.
- Ensuring that the person's overall health is monitored and assessed, and that appropriate treatments are given. A diagnosis of Alzheimer's disease or other dementia does not automatically prevent the presence of other health concerns and diseases. Failure to treat other illnesses can worsen the symptoms of the disease.
- Providing living space that is safe, familiar and provides a sense of security, while allowing the person to maintain 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 each person's needs and focuses on abilities rather than losses.
- Acknowledging and recognizing that the person's 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 the disease are to be valued and should be treated as individuals.
- Recognizing that all actions and behaviours of people with the disease are meaningful and reflect a desire to communicate something.
- Recognizing that the quality of life of the person with the disease is closely linked to the quality of life of the caregiver. As the disease progresses, the connection between the two becomes 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 the disease, understanding how it progresses and learning how to communicate with people with the disease.
- 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 get 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 someone with dementia, to ensure that one's health is monitored and appropriate treatments obtained.
- Becoming aware of one's own feelings and reaction to stress. Taking care of one's needs throughout the course of the disease.
- Planning for changes, 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 the 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 with dementia. When conflicts arise, communication, information, self-awareness, support and understanding can help caregivers find solutions to ensure that their own quality of life does not become a casualty of the disease.

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 www.alzheimer.ca/en/We-can-help/Resources/Alzheimer-Society-brochures-and-publications

Alzheimer Society

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