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# Care for patients with dementia

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## ABSTRACT

**Introduction:** Dementia is caused by an interaction of genetic, environmental, and lifestyle factors. It has grown into a major challenge for the public health system in the Czech Republic and around the world.
**Aim:** National strategies for dementia have been developed in a number of European countries. The strategies emphasize the need to support families, as it is often them who care for people with dementia. This article aims to present basic information about dementia, with a special emphasis on the management of patients with dementia.
**Methodology:** The article is a literature review. The data were sourced from the latest publications and recommendations of the Ministry of Health of the Czech Republic and the Czech Alzheimer Society.
**Findings:** The article presents significant data about dementia and the management of patients with dementia.
**Conclusions:** Given that the numbers of patients with dementia are expected to grow, society needs to be prepared and have adequate resources ready for both home and institutional care.

## KEY WORDS

Dementia, Alzheimer's Disease, nursing care

## LITERATURE OVERVIEW QUESTION

Dementia has become a top challenge for the public health system in the Czech Republic and around the world. In addition to risk factors, early diagnosis, and follow-up therapy, attention needs to be paid to the management of patients with dementia and to providing adequate tools for home and institutional care.

## BACKGROUND

The world population growth is accompanied by a range of problems concerning public healthcare. While the greatest threat of the nineteenth century was mainly infectious diseases, in the twentieth century it was cardiovascular, metabolic, and cancerous diseases. The twenty-first century is the century of degenerative diseases, namely nervous system diseases associated with dementia. The prevalence of these conditions, particularly Alzheimer's disease (AD), which is the most common form of dementia, is expected to increase significantly and rapidly with the ageing of the population.

Caring for people with dementia is increasingly becoming a priority for many countries around the globe. A number of European countries have developed their national strategies for dementia. The strategies emphasize the need to support families, who are the primary institution caring for people with dementia.

Dementia is the cause of the highest number of DALYs (Disability-Adjusted Life Years) in old age, which means that it leads to the highest number of years lost due to early death, and leaves the sick with a poorer quality of life for many years. (1, 2, 3).

Dementia correlates with a decline in cognitive functions such as memory, attention, thinking, and intellect. Personality suffers a gradual decline. The person is unable to perform everyday activities. Dementia is one of the main causes of dependence and disability

in old age. It ultimately leads to death, caused either indirectly or by direct failure of vital functions (4). An early symptom of the condition is memory loss. It first affects recent memories, and as the disease progresses, long-term memory becomes impaired. A decline in skills is implicated, followed by speech impairment (incomprehensible communication and mispronunciation), which may damage social contacts. Advanced stages of dementia may involve other malfunctions, such as behaviour changes including restlessness or aggressiveness, and perceptual disorders associated with delusions and hallucinations (5). This article aims to present significant data about dementia and the management of patients with dementia.

## DESCRIPTION OF THE RESEARCH STRATEGY

Data for this literature review were sourced from the latest publications and recommendations of the Ministry of Health of the Czech Republic and the Czech Alzheimer Society.

## LITERATURE OVERVIEW

### Dementia syndrome

The **ABC** concept is an assessment tool for the dementia syndrome:

- **A (Activities of daily living)** – everyday tasks (washing, dressing, eating). Other activities of daily living include cooking, shopping, transportation, and household finances. Information about these activities is obtained by interviewing the patient or their family. Supplementary questionnaires include the *Functional Activities Questionnaire (FAQ), the Disability Assessment for Dementia (DAD),* and the *Bristol Activities of Daily Living Scale (BADLS).*
- **B (Behaviour)** – (mood and behaviour changes) apathy, aggressiveness, bouts of depression, sleep disturbances, wandering, increased fatigue, eating disorders.
- **C (Cognition)** – cognitive functions. Neuropsychological tests are used for assessment, for example the Addenbrook Cognitive Test (ACE-R) examining executive functions (6).

### Prevalence and incidence of dementia

Almost 48 million people worldwide suffer from some type of dementia, of which 58% live in low- and middle-income countries. Estimates drawing on the World Health Organization (WHO) data maintain that approximately 152 million people will have dementia by 2050. The number of patients living in Europe is expected to double and reach 20 million. There are 7.7 million new cases of dementia worldwide each year, with an estimated one new patient every 3 seconds (7).

The Czech Republic (CZ) currently has approximately 153.000 people with dementia. According to the Czech Alzheimer's Society, 1 in 13 people over the age of 65, 1 in 5 over the age of 80, and one in two over the age of 90 suffer from dementia. Based on qualified estimates, 183.000 people with dementia are expected to be living in the Czech Republic in 2020 and up to 383.000 in 2050 (8).

### Alzheimer's disease and its stages

Alzheimer's disease develops slowly and inconspicuously. The disease has three stages based on the severity of the loss of memory and independence:

1. The early stage is marked by learning disturbances associated with poor short-term memory. The patient often misplaces items, may forget about daily tasks, is easily offended, selfish, suspicious. The patient remains independent at this stage.
2. The middle stage is characterized by advancing memory problems. The patient is disoriented in space and time, often unable to remember the names of the carer or family members. The personality changes continue to deteriorate. Self-sufficiency is severely disturbed. Patients are no longer able to carry out everyday activities such as cooking, dressing, and washing.
3. The late (advanced) stage is marked by a near complete loss of memory. Cognition and perception are severely disturbed at this stage. Patients do not recognize their family and friends and need full-time assistance. They also suffer from incontinence, are confined to a wheelchair, and generally decay physically and mentally (9).

The Czech Alzheimer's Society lists the first 10 symptoms as warning signs of AD risk:

- memory loss affecting the ability to perform common tasks at work,
- problems with carrying out daily activities,
- problems with speech,
- time and spatial disorientation,
- poor or deteriorating rational judgment,
- problems with abstract thought,
- misplacing items,
- mood or behaviour changes,
- personality changes,
- loss of initiative (10).

### Management of people with dementia

Caring for people with dementia is extremely challenging. It is often associated with an increased burden

on the health of carers, particularly where people with dementia are no longer self-sufficient and need assistance with everyday activities, and where there are behavioural disturbances. Behavioural abnormalities in people with dementia pose a serious problem for carers, one which they are often unable to deal with without professional help. Patients with behavioural problems therefore often need to be hospitalized or placed in care homes. If care is provided in a care home, the facility needs to provide adequate conditions and staff qualified to care for those with dementia.

Early diagnosis of incipient dementia is vital for maintaining the best possible quality of life for patients and their families. Prevention and early diagnosis, as well as new effective therapeutic approaches, could help to prolong the satisfactory quality of life of patients and their families.

Another significant problem in caring for people with dementia is the financial aspect. Increased costs involve health care, materials, medicines, and other required services. Family caregivers tend to have a reduced income as a result of caring for the patient and are often forced to change or leave their jobs. Caring for people with dementia fundamentally affects the lives of family caregivers. It is a substantial physical and mental burden, and the above-mentioned financial and social aspects are not negligible either. These family members unintentionally become "hidden victims" of dementia (1).

The need to take care of a loved one often arises suddenly and the family is not prepared for the new situation. They are often unable to cope with the demands of caring for a patient with progressive dementia. Caregivers tend to fail in their role for a number of reasons. The family is often unprepared for the long hours and complexity of the care, for the helplessness as the condition gradually deteriorates, and for the inability to communicate with the patient. Although family members often manage to care for the patient for several months or years, in the end, as the condition deteriorates, the patient is placed in a residential facility for patients with dementia.

The transition from home to a residential facility often carries a great emotional burden, both for the patient with dementia and for the caring family. Moving is a substantial stressor for older people. Social contacts are disrupted and their rhythm of life undergoes a significant change. The families also tend to experience a number of emotions associated with the feeling of failure to control the care and life of a loved one. It is necessary that both the patient and their family adapt to the new situation. Providers of care giving facilities need to strive to reduce the burden of adaptation to the new environment and to support and work with the family.

Cooperation with the family and support for family members is essential regardless of whether hospitalization is short-term or long-term. Communication with the family is as vital as communication with the patient. The patient's family and loved ones are partners in care and it is important to recognize that in many cases, they also need the support and help of a professional team.

The residential facility taking care of the person with dementia should be welcoming, friendly, safe, and respectful of patient dignity. Such facilities should deliver/enable a person with dementia not only care for basic needs, but also offer other useful activities enhancing patient dignity at the end of life.

Long-term care, as mentioned above, is not limited to institutions only. Most people with limited self-sufficiency live at home and receive care from family and outreach and outpatient social services. The quality and method of care depend on the family and the support and services available to the family. The more severe the disability, whether physical, mental, sensory or combined, the more important the supporting role of the community. The system needs to be friendly, accommodating, empathetic, approachable, non-discriminatory, aware of the disability and human needs, and last but not least, integral. (11, 12, 13, 14).

The home of a person with dementia needs to be safe. It is very important to communicate with the patient, and the communication needs to be calm, clear, understanding, and friendly. The patient needs to have regular daily activities in which they actively participate, such as washing, eating, chores, as well as walks, visits with friends, reading, and hobbies (13). Another recommended activity is cognitive training.

A number of cognitive centres in the Czech Republic specialize both in the diagnosis and treatment of dementia, and cognitive training.

A list of cognitive centres:

- Cognitive Centre, Department of Neurology, 2nd Faculty of Medicine, Charles University in Prague and Motol University Hospital
- Centre for Cognitive Disorders, 1st Department of Neurology, Faculty of Medicine, Masaryk University and St. Anne's University Hospital in Brno
- Centre for Diagnosis and Treatment of Neurodegenerative Diseases, Department of Neurology of the Olomouc University Hospital, and Faculty of Medicine of Palacký University Olomouc
- Cognitive Centre, Department of Neurology, Ostrava University Hospital

- AD Centre - Department of Cognitive Disorders, National Institute of Mental Health
- Centre for Cognitive Disorders, Department of Neurology, 1st Faculty of Medicine, Charles University in Prague and General University Hospital (15).

An amnestic form of mild cognitive impairment, accompanied mainly by memory impairment may be diagnosed prior to dementia. People with mild cognitive impairment usually do not need special care as they remain self-sufficient. Delaying the transition to a more severe form of cognitive deficit depends on cognitive training and prevention of other risk factors such as cardiovascular and cerebrovascular diseases, for example coronary heart disease, diabetes mellitus, hypertension, and stroke. Clients need to adjust their lifestyle, focus on a healthy diet and exercise, and avoid smoking and drinking alcohol (16, 17).

## RESULTS

The global population is aging and the risk of dementia increases with age. Dementia does not equal aging, as it results from disease. Although no cure is available yet, it is possible to relieve and assist long-suffering patients, under the mission and goals of health and social care. Care for those living with dementia is becoming a fundamental priority for many countries around the globe.

The quality of life of a dependent senior cared for by their family is significantly higher compared to institutional care. At the same time, these caring families save society considerable expense as family care is much cheaper compared to any institutional care. On the other hand, many seniors live alone without their family.

Given that the numbers of patients with dementia are expected to grow, society needs to be prepared and have adequate resources for both home and institutional care.

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