Care for Dementia Caregivers in Bulgaria.

State and Good Practices

Published by FSSB, the report Care for Dementia Caregivers in Bulgaria.

State and Good Practices seeks to research and deepen knowledge of key issues affecting

Dementia caregivers in the country, and to map solutions that might improve the state of all those affected by dementia.

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Cover photo: A woman trying to concentrate on a candle. © Photo by Kindel Media: https://www.pexels.com/photo/wood-light-fashion-woman-8172886/

Content:

1. Executive Summary

Dementia Caregivers – those who are responsible for the health of their loved ones or work in institutions in Bulgaria, seem to be left alone in the arena against a syndrome whose manifestation is perceived as shameful, due to a lack of understanding of its essence. Such an attitude towards the syndrome carries the legacy of socialist conciliation and silent shaming of the other, who fails to fit into the ideal of a socialist society. It is better not to talk about it – to pretend that the problem does not exist. Such an attitude hinders the development of knowledge about the syndrome not only among people who directly care for the demented, but even among general practitioners, the so-called GP. However, it is not only stigmatization that hinders early diagnosis and detection of the syndrome. It turns out that the country does not have a national strategy for dementia patients. Despite the efforts of the non-governmental sector, there seems to be disintegration and an absence of partnership between the third sector, local government and national institutions. This attitude leaves the two NGOs dedicated to Alzheimer's and dementia completely alone in the fight for any progress in dementia care.

This picture shows why caregivers are burning out, whether they are involved in formal or informal care for people with dementia. With the exception of a few good initiatives driven entirely by NGOs, there are no targeted efforts to raise awareness of dementia among the population, to train healthcare professionals or to support caregivers. There is a lack of accessible and free training resources for working with dementia, not only in small towns but even in large cities. Statistics on dementia sufferers are inaccurate. The National Care Strategy and Plan have good intentions for introducing measures affecting care in the country, but they remain only on paper.

The report critically examines all these circumstances, trying to look at the systemic gaps as an opportunity to organise supportive measures. In this regard, the focus is not on the shortcomings as a doom for those affected by dementia, but on developing the few good practices in the country and maximising the exposure of caregivers to the benefits of care.

2. Background situation

2.1. What Is Dementia

According to the private American academic medical centre for integrated healthcare and education Mayo Clinic, dementia is a general term that describes a decline in cognitive function, interfering with a person's daily life and independence. It affects memory, thinking, communication, and social abilities. Dementia is not a single disease but rather a set of symptoms caused by various conditions, most commonly by Alzheimer's disease. Other causes include vascular dementia, Lewy body dementia, and frontotemporal disorders. The syndrome is a combination of related symptoms or conditions. Dementia encompasses various clinical conditions. It is irreversible, and its consequences are devastating. Common symptoms of dementia include:

- Memory loss and forgetfulness
- Difficulty concentrating or solving problems
- Delayed responses when performing tasks
- Struggles with speech, vocabulary loss, or finding the right words
- Disorientation and confusion about time and place
- Getting lost, even in familiar surroundings
- Sudden changes in mood, including irritation or agitation
- Feelings of paranoia or believing others are plotting against them

As the condition progresses, individuals may require constant supervision and assistance with daily activities, such as eating, dressing, and hygiene.

3.2. Who Cares for People Living with Dementia in Bulgaria

Care and social services for older people and people with disabilities in Bulgaria are provided by formal and informal organisations. Formal care is offered by trained professionals in specialised institutions, through community-based services, or at home. Informal care is provided by family members within the household.

In Bulgaria, family members are still the primary caregivers for older people, especially those with complex health needs. Even when they hire additional care support at home, family members continue to bear the primary responsibility for their sick loved ones and perform the main caregiving activities. Since the 2003 restructuring of the social services system, the availability of community- and home-based services has expanded. However, support for people living with dementia and their families remains limited.

Caring for a relative with dementia often restricts caregivers' ability to work or stay employed. This can lead to reduced access to social security and healthcare benefits, and increases the risk of economic instability and social isolation for caregivers.

The country's residential and assisted living facilities have remained unpopular and underdeveloped. As Goncharova and Karamelska point out, since 2010, two non-governmental organisations—Alzheimer Bulgaria and Compassion Alzheimer—have become actively engaged in addressing the challenges faced by people living with dementia. Both organisations have produced valuable reports and surveys that enlighten the needs of those affected.

The National Strategy for Long-term Care acknowledges the serious challenges posed by Bulgaria's ageing population, including the increasing demand for long-term care services and the associated rise in public spending. The strategy points out that in the coming years, more and more older adults will lose their independence, requiring intensive support. Despite this negative forecast, the country lacks a comprehensive and adequate vision and strategy to ensure sustainability in providing a decent life and care for this population.

It is assumed that people suffering from dementia in Bulgaria are 100,000, and out of them at least 50,000 suffer from Alzheimer's disease[1]. A nationally representative study in 2018 points out that 1.61% of the population in the country suffers from dementia, and Alzheimer's disease prevalence is 0.39%. 24.34% of all the patients with dementia suffer from Alzheimer's disease. According to Alzheimer Europe's data[2] in Bulgaria, a total of 108,884 people suffer

[1] http://ec.europa.eu/health/ph_information/dissemination/echi/docs/dementia2_en.pdf
[2] https://www.alzheimer-europe.org/dementia/prevalence-dementia-europe?language_content_entity=en

from dementia in 2008, of whom 34,290 were men and 74,594 were women. The expectation is that the 1.54 % of the population suffering from dementia would rise to 2.47 % to 2050. "Though these values are widely accepted, there is a strong need for a dedicated epidemiological study that would document the actual prevalence in Bulgaria. The availability of accurate data would contribute to the optimization of treatment, medical, and social care for patients with dementia, which are at present neither well developed nor reimbursed by the National health insurance fund."[3]

There is no data for the direct and indirect costs incurred by the country concerning home-care patients suffering from dementia. According to the National Strategy, Bulgaria supports 14 Homes for adults with dementia that can accommodate 825 patients. The "Civil Association Alzheimer Bulgaria" provides information about 23 specialised centres and homes for the elderly in Bulgaria. The NGO has received assurances that those centres and homes can accommodate people suffering from Alzheimer's and dementia.

As Family care remains the most widespread form of support for people living with dementia in Bulgaria, assistant support is a key social service that enables individuals to remain in their home environment. Since 2021, municipalities have provided this service as a state-delegated activity funded by the national budget.

It is available to:

- Older adults unable to care for themselves, without officially recognised disability status;
- Children and adults with permanent disabilities who require assistance and are not receiving similar support under other laws.

Assistant support includes help with personal care, mobility, daily tasks, and communication, based on individual needs. While primarily home-based, it is not limited to the home setting.

3.3. Why It Is Important to Understand the Needs of Caregivers

[3] Dimitrov, I., Tzourio, C., Milanov, I., Deleva, N., & Traykov, L. (2012). Prevalence of dementia and mild cognitive impairment in a Bulgarian urban population. *American Journal of Alzheimer's Disease & Other Dementias®, 27*(2), 131–135. https://doi.org/10.1177/1533317512440490

There is the notion that care stands one step lower than help, and there is even a lower step of it – support[4]. It almost sounds like animation for people who are ill. According to a report by the Alzheimer's Association and the Alzheimer's Compassion Foundation[5], the wider social environment, including family and friends, plays a decisive role for people with dementia - both the patient's condition and the extent to which professional care is needed depend on them. For this reason, the provision of support and information should be aimed at both patients and people from their close social environment. Therefore, it is vital to understand the needs of caregivers of people with dementia.

3.3.1. The burden of care ties the caregiver's hands

The term "Care Burden" is associated with negative consequences for the physical and mental health of the caregiver. The two Alzheimer NGOs in Bulgaria highlight that at least one family member, often of working age, is unable to perform economic activity (i.e. work) due to full-time engagement in care. This creates financial strain on the family, leading also to economic losses for the whole society in the form of higher unemployment and lower productivity.

- At least one family member is unable to take care of his or her own needs, as he or she is fully engaged in caring for the patient;
- Being unable to care for themselves, at least one family member suffers from poor mental and physical health;
- A caregiver with poor health will give a lower quality of care even to their loved one;
- A caregiver with poor health combined with the lower quality of care leads to a higher need for health services for the patient and the caregiver, which creates a greater burden on the health system.
- Excessive burden of caring for a patient with dementia can lead to social isolation of the whole family.

Table 1: *Changes in the lives of caregivers*

[4] Stoyan Stavru in Life with Dementia, Vox Nihili, https://soundcloud.com/discover
[5] https://shorturl.at/iyuGs

Statement % respondents	Time for me	Time for the family	Time for friends	Conflicts in the family	Anxiety of the patients	Rest
strongly agree	57,60%	37,50%	47,10%	21,90%	58,80%	42,90%
Agree	30,30%	34,40%	35,50%	40,60%	41,20%	25,70%
Neutral	6,10%	15,60%	14,70%	18,80%	0,00%	20,00%
Disagree	6,10%	9,40%	2,90%	15,60%	0,00%	5,70%
Strongly Disagree	0,00%	3,10%	0,00%	3,10%	0,00%	5,70%

Source: *Alzheimer Bulgaria, 2012*

Read as Caregivers' Needs, those may sound like:

- ✓ Time for caregivers – opportunities to rest, refresh and maintain a life beyond caregiving;
- ✓ Quality time with their family – support to balance roles and stay in healthy relationships;
- ✓ Social connections – space for friendships and personal interests outside the caregiving;
- ✓ Conflict prevention and resolution – informal support to manage balancing of roles and family tensions;
- ✓ Access to practical guidance – clear, accessible educational information on how to meet patients' needs and reduce their anxiety.
- ✓ Integrated support systems – combining formal daily help (e.g. hygiene, meals, cleaning) with emotional and psychological support for the caregiver.

Another key problem that caregivers describe is the patient's nutrition. In this sense, providing group meals in daycare centres, allowing for socialisation and shared pleasure, is defined as one of the most important activities.

Caregivers report a need for accurate information and more support for the family. The lack of information is frustrating because it requires the caregiver to spend a lot of time and become a detective, exploring completely unknown territory. This often requires communicating anonymously in forums such as those on the BG MAMA portal, where they can at least find empathy and various ideas for dealing with crises.

In addition to financial costs, caring for a patient with dementia is also a serious expense of time. According to the survey data, it takes an average of 15 hours a day, with one-fifth of respondents taking on this burden without help. Almost all participants in the survey do not find time for themselves, their family and their friends, and nearly two-thirds never go on vacation.

As a whole, caregivers seem to transition from one role to another, experiencing a hybridisation of roles that are not always their usual positions within society. At one moment,

a caregiver is a daughter; the next, she becomes a mother to her mother, simultaneously taking on the roles of psychologist, nurse, and social worker. All the while, she is expected to remain a full participant in her own family life—as a wife, a mother, and a homemaker.

3.3.1. How can you heal what you don't understand?

In their study *Care of People Living with Dementia in Bulgaria: Between Over-Responsibility to the Family and Distrust in Public Health Services and Policies*, Galina Goncharova and Teodora Karamelska highlight the serious gaps in support for dementia caregivers in Bulgaria. They show that families caring for loved ones with dementia often receive little to no help after a diagnosis. There are no clear systems in place to ensure early diagnosis, follow-up treatment, or structured care plans—measures recommended in the *World Alzheimer Report 2022*.

The study also reveals that even professionals working in relevant institutions struggle to explain what forms of formal and informal support are available. Many were unclear about definitions and reported "blind spots" in both policy design and practical implementation.

Caregivers' own stories reflect a general lack of public awareness and advocacy for people living with dementia. Taking care of people with dementia leaves no one the same. Transformation is hard to accept and understand, unless people receive support in their resilience despite the enormous social and economic burdens.

However, caregivers often struggle alone. They are expected to carry overwhelming responsibility while receiving little material and moral recognition or support from either public or private health and social care systems. Many face exhaustion and even blame for not doing enough.

Their personal stories also outline a common "trajectory" of dementia care. Most caregivers describe the beginning of their journey with feelings of shock and confusion. Later, they reflect on signs they had missed – like memory lapses, forgetting names or holidays, or getting lost—symptoms now recognised as early indicators of dementia.

For many caregivers, a late diagnosis of dementia meant being suddenly thrown into the middle or advanced stages of the disease, without any preparation for what was coming. They

were quickly confronted with overwhelming and frightening behaviours, described as “scary stuff” or even “insane behaviours.” These included unexpected aggression or anger, delusions (firm beliefs in things that aren’t real), anxiety, severe memory loss, depression, wandering while disoriented, refusal to take medication or bathe, disrupted sleep, and even self-harming.

It is difficult to face such changes, as people feel emotionally exhausted. Many caregivers compare it to a mourning process. They have to “rediscover the world,” letting go of what they knew and believed, even deeply held religious values, to cope with the new reality of the person they were caring for. It is a painful, but sometimes clarifying, emotional shift.

Often, trauma is intensified by the mismatch between what caregivers *know* about dementia in theory and what they *experience*. Even when you might have heard about the disease, living through it is a very different, much raw reality.

In Bulgarian society, dementia might often be seen as just a part of ageing, something natural and expected. This perception puts barriers to early diagnosis, reducing the urgency to act. When symptoms become obvious – such as forgetfulness, odd behaviour, or confusion – people sometimes dismiss them as the insulting “just sclerosis”. Shame is often the result of people making fun out of the new condition of people with dementia, and caregivers often are judged for not trying hard enough to help those in need. The phrase “Ignore them, they’re sclerotic” reflects the social stigma and lack of understanding around dementia.

Goncharova and Karamelska argue that strong cultural beliefs lay down such a stigmatising attitude. First, there is a tendency to exclude those who don’t fit social norms. Second, as back then during socialism, people had a well learned reflex to hide what could be seen as “abnormal” to preserve their reputation. And third, dementia is often reduced in the public mind to senile behaviour, a simple cognitive decline. Because of this stigma, many family members and older people try to hide early signs of dementia. They avoid talking about memory loss or changes in behaviour, staying unprepared, often even being shocked or going through a stage of “catharsis” when things get harsh.

In most of the cases studied by Goncharova and Karamelska, family members who tried to educate themselves about dementia felt discouraged and defeated. Medical professionals often offered little help, with some even saying things like, “Nothing is certain, nothing can be done.” A major reason for the discouragement is the complete lack of a structured dementia

care pathway in Bulgaria, including a national vison and strategy. There are no clear steps to follow after diagnosis, no coordinated system of healthcare providers, and almost no additional services for caregivers, like support groups or counselling.

Bulgaria (along with Greece and Romania), lacks clear medical and legal guidelines for diagnosing and assessing dementia. This means families are often left to navigate a confusing and fragmented system on their own.

Five specialised Alzheimer's disease committees in Bulgaria, located in major cities – Sofia, Varna, Pleven, and Plovdiv, focus on helping families, while people in rural areas remain isolated from the system. Even when families manage to arrange an appointment for a specialised medical visit, they have to wait for months, and the situation gets worse in the meantime.

Systemic challenges confront early diagnosis, and even when they manage to organise for it, caregivers face a lack of institutional support. Over the past decade, there have been very few public information campaigns, local governments rarely receive assistance in creating daycare centres, and there is a lack of accessible guides or advice based on successful practices in other countries. In many cases, caregivers simply hear: *"No one can help you."* This, in turn, leads to emotional exhaustion and complete discouragement. It is not rare that the caregiver even requires medical treatment themselves for depression or burnout. A generation crushed by responsibility, for taking care of ageing parents while at the same time being a parent and grandparent. Where formal support is absent, and informal help is oppressed by stigma, there is a lack of community, and so the burden becomes unbearable. Many caregivers end up balancing various roles – a doctor, a patient, an administrative assistant to go through procedures, a psychologist to support mentally and emotionally the sick, and still a family member to all the people she loves. You have to learn about the disease while developing practical care skills… The overwhelming responsibility strips caregivers of their strength. Personal freedom, identity, and confidence no longer remain within their grasp. Neighbours and family members might keep their distance, often being afraid of the unpredictable and sometimes alarming behaviour of people affected by dementia – falls, self-harm, aggression, hallucinations.

Table 2. *Struggles Faced by Dementia Caregivers in Bulgaria*

Struggles Faced by Dementia Caregivers in Bulgaria		
Struggle Area	**Caregiver Challenges**	**Policy Opportunities**
Cultural and Moral Expectations	Strong sense of filial duty; institutional care perceived as "abandonment."	Public discourse and policy narratives could redefine care as a collective responsibility involving the state and society.
	Care often perceived as a family moral obligation, rather than a shared social responsibility.	
Stigma and Social Devaluation	Caregivers face stigma and a lack of material and moral recognition	The government could create a legislative canvas for professional recognition and regulation, supporting a better balance of caregiving vs other social roles (i.e. professional, family).
	Informal caregivers feel the burden of judgment; Lack of support.	The private and public sectors could cooperate in organising awareness-building campaigns focused on educating and changing public beliefs and attitudes.
Lack of Care Infrastructure	Early diagnosis and post-diagnosis of the disease are not organised. GPs lack training for working with patients and their families.	The draft national dementia care strategy should be carefully revised and implemented, providing standardised care mapping.
	Limited access to specialised diagnostic and support services, especially in rural areas.	Services should be provided in rural areas, reaching the population affected by the disease.
Distrust of Institutional Care	Poor quality, low capacity, and lack of transparency in care homes discourage families from seeking institutional care.	Regulatory oversight of the quality of institutional care needs to be improved (e.g. through normative acts on relevant care institutions)
		No caregiver inclusion in care planning.
Limited Community-Based Services	Municipal services (apart from social assistance) are limited to cleaning and food delivery.	Home-care and day-care programs must be integrated as community care services.
	Hourly caregivers are often untrained or unaffordable.	Better certification and/or quality monitoring of non-institutional care. Improved communication between NGOs and municipalities. Government incentives to the NGO sector providing care services; more project financial resources dedicated to non-institutional care.
	Fragmented and inconsistent care support.	

Financial Burden	High costs of private care.	Caregiver allowances or fiscal incentives.
	No financial incentives, such as tax relief, i.e., for family caregivers.	Public-private cost-sharing models.
	Insufficient public investment in dementia care.	
Psychological burden on Carers	Chronic stress, emotional exhaustion, and depressive episodes.	Creation of accessible programs for psychological support, respite care, or training for caregivers.
	Carers become both "doctors and patients."	
Social Isolation	Carers are left alone; few support networks.	Structured peer support or community mobilisation.
	Friends, neighbours, and relatives rarely assist due to stigma or fear of behavioural symptoms.	Inclusive community groups for communication around dementia behaviours.
Lack of Information and Guidance	Carers face the disease without guidance, both at the beginning and during the terminal stage.	National awareness campaigns provide accessible educational resources for families.
	Trust in institutions erodes over time.	Institutional care navigation support (i.e. what steps to take, what necessary procedures to pass, which institution to visit).
Historical and Systemic Roots	The legacy of socialist/post-socialist familialism (prioritising family above all) combines with neoliberal withdrawal of state care provision.	A need for an integrated, historically informed policy that bridges cultural norms with modern welfare models.

Source: current report

This lack of community support and solidarity only adds to the caregivers' sense of isolation. It is not just the disease itself, but the collapse of shared responsibility in society that makes the caregiving journey even harder.

The belief that only family members can provide the best and most loving care – what is often called the "moral duty" to care – is not simply imposed from outside. Caregivers themselves internalise it, even when they feel overwhelmed. At the same time, professional caregivers

and home aides often shared with us that they feel judged or distrusted, suspected of caring only for money. One home assistant said plainly: “They treat you like a second-class person.”

There is still a widespread belief in Bulgaria that this kind of care work should only be done by people who are retired, poor, or otherwise unable to find a “real job.” Paid caregiving is seen as low-status and undesirable – even when the people doing it are skilled, compassionate, and essential.

For family members, the idea that children owe their parents unconditional care – what many call “filial duty” – remains deeply ingrained. It is both culturally expected and emotionally powerful. In Bulgaria, this sense of obligation is not only a traditional value, but it has also been shaped by both socialist ideology and current laws. Caregivers are rarely encouraged to question it.

To decide to move a parent or loved one into a nursing home is a painful and difficult choice. It is often seen by caregivers as an act of betrayal or abandonment, rather as a necessary step to take care of themselves. The reality also does not support another type of choice – poor conditions in most residential care homes, lack of trained staff, high staff turnover, and weak communication with families and no involvement of caregivers create a frightening perspective. Institutionalisation looks like stripping loved ones of dignity and reducing them to a state of mere physical survival.

Distrust of formal institutions only strengthens the pressure on families to provide care at home, reinforcing traditional expectations. As a result, the most common form of outside support remains minimal: services provided by the municipality (like food delivery or cleaning) or paying someone privately by the hour to help with hygiene or household tasks. Yet caregivers constantly face a dilemma: where to find someone trustworthy and competent? Many agencies charge high fees, send undertrained staff, or refuse to help with all the needed activities.

There is no clear, public data on private residential care services in Bulgaria, which exist in a legal grey area. And due to the high prices charged by private care homes and day centres, most families simply cannot afford to use them – forcing care to remain home-based.

In gerontology, dementia is sometimes called “a disease of the relatives” because of the relentless emotional and psychological toll it takes on caregivers. Facing the slow and unpredictable progression of the disease leaves many caregivers feeling trapped in the present, unable to imagine a future for themselves.

Isolation, combined with a lack of societal support, steals any perspective for professional growth, personal relationships, or even rest. Caregivers often feel stuck between generations, caught between cultural norms and the economic pressures of a society that provides little help. Inherited ideas of family responsibility and the harsh realities of a fragmented, underfunded care system.

From the moment they first encounter signs of the disease—at the “entrance,” as some call it – caregivers are left on their own, without guidance or reliable public information. And by the time they reach the “exit,” they are often even more disillusioned with the state and its institutions. Their journey is shaped by the lingering mix of socialist-era expectations and post-socialist individualism, in a system now heavily influenced by neoliberal values that offer no meaningful support.

Non-qualified people still face barriers in providing caregiving services. The absence of material and moral recognition for this work limits the development of the activities as part of the economic sectors. If improving the quality of the provided care is a key objective of the country, then establishments, structure and staff professional capacity must be leveraged, while control and observance of the criteria and standards in providing social services should be strengthened. A key document outlining standards of care for caregivers in Bulgaria is the Draft National Dementia Strategy (2014–2020). Although it was developed by leading experts, including Prof. Latchezar Traykov from the Expert Centre of Dementia Care at Alexandrovska Hospital, the Draft Strategy was never officially adopted by the Bulgarian government. Hence, Bulgaria remains among the European countries without an official national dementia strategy. However, the Draft Strategy contains valuable insights into the needs of people with dementia and their caregivers. The Strategy, i.e. emphasises the significant physical, psychological, and financial burden experienced by family members and informal caregivers.

The document highlights a growing need for scientific research on the needs of caregivers and different therapeutic and care interventions. We track what the expected systemic changes are in the next chapter.

Picture 1. *Gaps in the healthcare of people with dementia**

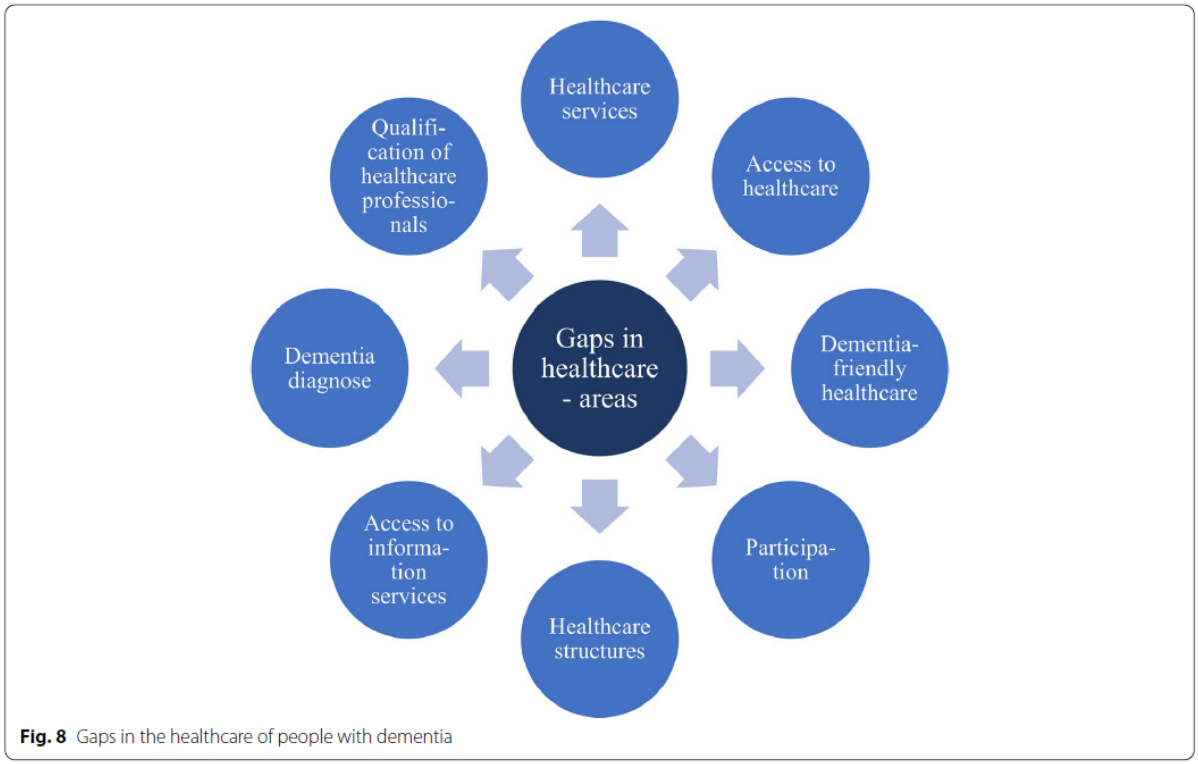

Fig. 8 Gaps in the healthcare of people with dementia

Source: Schmachtenberg *et al. 2022*

*The current research finds all these areas of gaps to be relevant for Bulgaria

4. Objectives of the Research

This research aims to identify gaps while mapping current and proposed best practices for dementia care, established by NGOs, government institutions, or researchers. The objective is

to serve as a practical tool in informing a comprehensive online platform designed for the needs of informal caregivers of people living with dementia.

More specifically, the research aims to:

- Point to policy gaps and suggest how they might be overcome
- Map existing practices and assess their effectiveness.
- Highlight promising practices that have not yet been implemented, including simple, practical caregiving activities that can be done at home, even by those without professional training.

How does this translate into good outcomes for caregivers and people suffering dementia?

- **Policy Gaps:** An online platform could minimise the gap in coordinated public policy. Research into caregivers' needs and distance learning tools, such as online platform, might provide accessible educational material to families and people for prevention and in the early stages of dementia. A centralised platform compiling all available caregiver resources would be a concrete step toward addressing the gap created by the absence of a National Strategy on Dementia Care.
- **Training Needs:** In the absence of official standards, caregiver training modules offered with open access and combined in one place can practically support caregivers through a structured, standardised educational process adapted for the Bulgarian reality.
- **NGO Role:** Last but not least, the proactive efforts of the two Bulgarian NGOs working with people affected by Alzheimer's seem to compensate for the missing public infrastructure. A joint work with these organisations seems crucial. It might be a good idea to foster long-term, mutually beneficial partnerships with them for future national initiatives. In this way, the knowledge and effects of any steps taken to educate people in Bulgaria about dementia could be expanded throughout the country.

5. Methodology

5.1. Desk research

This qualitative research aims to draw a comprehensive picture of the reality faced by informal dementia caregivers in Bulgaria. The goal is not to produce an academic paper in the traditional sense, but to collect and analyse available knowledge in a way that is practically useful for policy recommendations and the development of an online caregiver support platform.

A systematic search will be conducted of academic literature, policy papers, evaluation reports, and civil society publications, using keywords such as:

- *"dementia care Bulgaria"*
- *"informal caregiving"*
- *"caregiver burden"*
- *"caregiver support services"*
- *"best practices in dementia care"*
- *"caregivers' needs"*
- *"supporting caregivers"*

Special attention will be drawn to:

- Bulgarian and European policy frameworks;
- Third sector reports and evaluations;
- Research by Bulgarian academics or institutions (e.g., health faculties, social science researchers);
- International practices that are potentially adaptable to the Bulgarian context.

The aim of this review is not to conduct a formal literature meta-analysis, but rather to map available practices and identify both structural and policy gaps, on the one hand, and practical - implementation gaps – on the other. Materials will be subjectively selected based on their relevance and potential to inform policy and caregiver support.

5.2. Practice Mapping

The research will also include a mapping of **existing practices**, both public and NGO-driven, as well as **unrealised or promising initiatives** (even if small-scale or informal). The focus will be on:

- Home-based interventions;
- Psychological and emotional support services;
- Training materials or programs (formal/informal);
- Access to institutional and non-institutional care;
- Digital and community-based initiatives.

Our attention will be on low-cost, replicable practices adaptable for use by informal caregivers, including those without formal qualifications.

5.3. Thematic Analysis

The thematic framework will concentrate on the following topics:

- Needs and burdens of informal caregivers;
- Availability and accessibility of services;
- Knowledge and training gaps;
- Social and institutional recognition;
- Community and policy engagement.

5.4. Limitations

The research is not nationally representative of the Bulgarian population. The intention is to understand the context of caregiver challenges and practical measures through the lens of developing a useful and user-centred online support platform.

As there is no centralised contemporary data on the number, profile, and needs of informal caregivers in Bulgaria, the comprehensiveness of the findings might also be limited.

Some useful materials or best practice examples may not be accessible due to the risk of competitiveness, which potentially excludes relevant data from the analysis.

The research is time-limited and resource-constrained, affecting the depth of field engagement and follow-up with informants.

The study does not aim to meet academic standards, so it prioritises practical applicability and knowledge gathering over methodological clarity. This may result in the lack of empirical robustness.

Due to social norms, caregiving is often carried out by women, and this may be reflected in the research. While men do participate in caregiving, they are absent from research findings, unless specifically targeted.

Last but not least, the researcher's interpretation involves a high degree of subjectivity on what may constitute a “promising” or “best” practice.

6. Findings

6.1. A person-centred approach

According to the Bulgarian Draft National Strategy for Dementia Care, the ultimate strategic goal for care should be a person-centred approach, including:

- Home-based assistance with daily activities
- Access to daycare centres
- Temporary and permanent accommodation services
- Mobile services within the community (e.g., food and sanitary delivery)
- Care in hospitals
- Emotional, psychological and practical support for families and caregivers
- Palliative care and crisis intervention

Additionally, the Draft Strategy proposes several targeted measures in support of caregivers:

- Developing an individual care plan by assigning a responsible professional (e.g., social worker, psychologist, neurologist, general practitioner);
- Individual needs assessment through a clear methodology;
- Specialised centres for consultation and coordination;
- Expanding and enhancing patronage (home visit) services.

The Draft Strategy also aims at educating family members and caregivers about the progression and specifics of dementia-related diseases, available care and treatment options, community-based services, and how to access support and training. More specifically, the proposed actions suggest:

- Local specialised centres for caregiver consultation and support;
- Regional information systems to connect health and social institutions, resulting in prevention, early diagnosis, post-diagnostic care, and crisis management;

- Professional and patient organisations providing training and guidance to families and caregivers through;
- Internet platforms and portals serving as educational media;
- Real dementia-friendly environments are needed to ensure people with dementia remain included in society.

6.2. Working with the system

A report by the Alzheimer's Association and the Alzheimer's Compassion Foundation states family members of people with dementia perceive day care centres as a protected space where their loved ones enjoy a healthy diet and are engaged in meaningful activities. The benefit is that people with dementia are out of the home and have the opportunity to socialise. In the meantime, caregivers also find time to take care of themselves, to relax or join informal meetings with friends or family. It appears daycare centres must develop further their service of offering information and support to families, including informal caregivers into the information loop and consider family members an essential part of the *caregiving team*. This could result in leveraging the overall motivation of family members to continue caring for the patient, thus postponing the need for residential care.

The caregiver as a figure is someone who knows best the individual patient, she knows how to avoid negative memories and evoke positive ones. She is capable of encouraging patients to share their hopes and concerns, to empathise people affected by dementia and take into account the specific condition of the patient. This is extremely important as it presupposes working with the system, rather than just trying to fight the symptoms of the disease (which might be quite discouraging).

A report suggests achieving empathy actually means living the dementia symptoms. Hence, caregivers should pass a training called "Feeling Dementia". As part of the training, prospective staff members have to perform simple daily activities with limited vision, hearing and concentration, guiding them in experiencing what it is like to live with dementia. The idea is that empathy brings caregivers closer to people with dementia and in this way the person affected by dementia can also join the team caring for him, rather than fighting against everyone in his world. Such approach reduces levels of anxiety and problem behaviour.

The concept of working within the system suggests that everyone – doctors, family members,s social workers, neighbours, closed ones perform a key role in the care for those with dementia. And of course, the central role remains for the dementia patient himself. The beneficial effect is for the condition of the sick, but as well for the whole family who otherwise lack information and might struggle with stigma, neglect and structural (institutional) barriers to take care of those they love. Engaging family members in the process, hearing their worries and concerns actually helps them overcome negative feelings. The more people are engaging in the system to support those affected by dementia, the more everyone might find a healthy balance between their hybrid roles. I.e. the family members may choose to focus on their own needs while someone else performs the main caring duties, if the community shows understanding and support. This approach advocates for building an informal network of support within the community. Of course, it is closely related to allocating more public financial and human resources to the development of practices that cross professional and institutional boundaries.

6.3. Community-based support

The Alzheimer organisations in Bulgaria suggest that local governments could assist farmers in creating green daily dementia care centres, where municipalities ensure the quality of services and the environment in which they are provided. The quality of the services relies on the successful cooperation between the farm, the municipality and the local community. Why might this be a good idea? Currently, families of the patients are the primary caregivers in terms of organising care and performing most of the chores. It is a big burden. Green-care centres can support fighting memory loss, involving patients in meaningful, yet highly satisfying activities, while at the same time leaving enough opportunities to integrate medical and psychological help. In any case, family members are not left outside the team. They are updated on the patient's progress and remain part of her life. The concept confronts residential care while supporting families to continue their usual everyday life.

It is why day centres must be improved, allowing patients to continue living in a family environment. The idea is to shift from healthcare to achieving a decent life, preserving autonomy, identity and sense of self-worth.

As Gabor Mate states – the informal support we receive when being ill is crucial not just to survive but to heal. Building a strong, community-based support system will improve remarkably the current status of dementia patients and caregivers. All available local resources, particularly those offered by NGOs, must be integrated in the field. Structured social interaction might inspire neighbours and relatives of people living with dementia to network in a support system through group activities. It will also strengthen the feeling of belonging and even a duty to people affected by dementia, enlightening them as equal members of the community. The community is the strongest core for supporting family and friends must with easy-to-understand, accessible information revealing the nature of dementia. Practically will help people to respond more effectively to difficult situations. Regular community meetings can serve as a safe space for exchanging knowledge, expressing emotional concerns, and receiving guidance. In this task church might serve as a focal point for open community engagement initiatives, such as informational open days, raising awareness, reducing stigma, and in this way changing attitudes and behaviour. These events might also

attract new volunteers and advocates to join the cause, expanding local daycare centres' capacity and support networks.

6.4. Good practices supporting caregivers in Bulgaria

6.4.1. Strategic Commitment for not (yet) Implemented Good Practices:

- ✓ Training and Support for Informal Caregivers
  Although the Long-Term Care Strategy foresees training, supervision, and counselling, the measures focus on formal professionals and do not systematically include informal caregivers. There is a lack of widely accessible programs for training, counselling, and supervision of families and relatives involved in caregiving.
- ✓ Online Services and Telecare
  Telecare and online services are not accessible in small settlements and rural areas. There is no clear system for informing, training, and supporting relatives on how to use these technologies.
- ✓ Insufficient Use of New Technologies and Personalised Solutions
  Geolocation devices, smart alarms, medicine dispensers, and similar tools are neither subsidised nor made available under affordable conditions. There is no national program for digital support of home-based care.

6.4.2. The ANTISTIGMA Training

Especially notable in Bulgaria is the caregivers' training through the ANTISTIGMA education intervention, which supports healthcare professionals and indirectly families in changing their understanding of dementia, as well as their abilities to communicate and manage it. Such an approach confronts two key dementia care system defects. Often, it is the medical system that appears ill-equipped to diagnose dementia early. Another painful barrier is the stigma surrounding the diagnosis – leaving caregivers isolated, dismissed, or afraid to seek help.

Implemented across four European countries, the program discloses how, through specialised training, general practitioners can comprehend clinical syndrome data while improving their ethical communication skills, empathy, and person-centred approach. In this way, GPs

become allies – part of the systemic approach to fight dementia. They deliver diagnoses with sensitivity, involve both patients and caregivers in decision-making, while helping them preserve their dignity. Families are seen as partners in the process who need to plan their lives.

Doctors no longer fear "harming" families with a dementia diagnosis and are becoming more supportive of caregivers to help them find clarity and early intervention. Better-trained general practitioners become caring partners to caregivers. Understanding and timely guidance grow within the collaboration.

The ANTISTIGMA initiative overcomes silence, shame, and struggle with the opposite - support, recognition, and shared responsibility. The training raises awareness and changes attitudes and behaviours within a key target group to build compassion, so caregivers feel seen, heard, and meaningfully included in the care journey.

In its Bulgarian edition, part of the EU's ACT ON DEMENTIA initiative, ANTISTIGMA helped caregivers—especially those with no formal geriatric training—understand *why* dementia changes a person's behaviour and how to respond without emotional escalation. As focusing on restoring the past or imposing external expectations is not productive, the training emphasises validating the patient's experience, not correcting it. Caregivers learned that they don't have to fight the fantasy or the confusion, but instead can relieve distress by accepting the person's truth in the moment. Of course, there is no universal manual to overcome the consequences of dementia. However, information about the emotional and cognitive shifts that come with the disease gives caregivers the strength to stop blaming themselves or the patient. ANTISTIGMA helps make this knowledge accessible. When caregivers shift from trying to bring their loved one "back to normal" to supporting their reality, something profound happens: the struggle gives way to connection. Empathy replaces control. The burden becomes more bearable. The relationship emerges as it is – changed, but grounded in good communication, empathy and care in its most heartfelt meaning.

6.4.3. The Alzheimer Café

Another very good practice of caring for the caregivers in Bulgaria is "The Alzheimer café – Friends of Dementia". It is a Mutual help group opening a space for family members of people

with Alzheimer's or other types of dementia. In this community, relatives of the sick can share their experiences, exchange hope, up-to-date information, and empathise. The rhythm of the group is once a month in a protected environment and a calm atmosphere, guaranteeing the confidentiality of group members and the information shared. Another benefit of the group counselling is that it is free for all participants, enabling families affected by the problem to share their experiences related to caring for the sick, to obtain up-to-date information, to receive and give support. The group provides active, diverse and full-fledged social contact for relatives who care for patients diagnosed with the disease. It reduces the feeling of isolation and reinforces the idea that even though each experience is individual, we are not alone in circumstances caused by dementia symptoms.

The mutual help group rhythm is monthly, providing an opportunity for members to discuss important topics, some of which are pre-planned and tailored to the group's needs.

The meetings are organised and held in a protected environment and a calm atmosphere, which guarantees the confidentiality of those present and the information shared.

Picture 2: The mutual support group's social media visual

6.4.4. Online consultations through website and Facebook

The Facebook page of Alzheimer Bulgaria supports family members and professional caregivers of people with dementia by providing accessible, timely, and practical information. Through regular posts, the organisation shares best practices for caregiving that address both emotional and organisational aspects of support. Visitors to the page can find advices about establishing a stable and predictable daily routine for their loved ones, integrating visual and audio reminders, special calendars, large clocks, and talking devices. Guidance is offered for organising everyday routines by reducing confusion and anxiety for people with dementia. A

good example is placing frequently used items in visible and logical places, labelling drawers and cabinets, and using phones with photo-based speed dialling.

Special attention is devoted to content focused on new technologies. The page promotes useful digital tools – GPS tracking devices, scheduling and reminder apps, and safety devices with automatic shut-off features. Additionally, Alzheimer Bulgaria offers free online consultations to families and sends personalised advice helping them feel more confident in the daily care. The Facebook page serves as a source of information and as a platform for mutual support, education, and the promotion of dignified care for people living with dementia.

7. Conclusion

Bulgaria in the 21st century still lacks a strategic vision for improving the lives of dementia caregivers. A well-intended Draft Strategy on Dementia Care still has not been adopted. The Long-Term Care Strategy and the Social Services Act demonstrate a clear understanding of the challenges faced by informal caregivers, especially those caring for people with dementia. However, any implementation of these commitments remains limited. Predominantly, the development of good practices for dementia caregivers in the country has been organised by the two NGOs in the Alzheimer's field – "Foundation Compassion Alzheimer" and "Alzheimer Bulgaria". Government-promised measures such as training, supervision, and counselling for informal caregivers are not yet systematically available or accessible. Similarly, the integration of digital tools such as telecare, geolocation devices, and smart medication dispensers remains underdeveloped, with no national subsidy schemes or structured support programs in place. All these gaps result in missed opportunities to improve the quality of life for both caregivers and care recipients and dramatically increase the risk of social exclusion and burnout among those providing care at home. Policy can translate into practice if both the government, local governments and the third sector organise and partner in a focused effort, developing and funding inclusive, accessible and user-friendly services. By reaching informal caregivers across Bulgaria, including those in rural and underserved areas, the good wishes in strategic intentions can transform into meaningful improvements for the lives of families affected by dementia. An online platform combining at one place all available resources for training of the

caregivers can be especially useful in educating Bulgarian population about the needs of dementia patients and how to respond adequately.

8. Annexes (links, resources, source list, contact list, etc.)

8.1. Resources for dementia caregivers training:

Physical Education Elders: Иновативен междусекторен комплект за обучение за професионалисти, работещи с възрастни хора (болногледачи и физически инструктори), пълна книга, достъпна напълно безплатно!: https://elders.globalhelp.ro/local/staticpage/view.php?page=the_project&lang=bg

Alison: Free Caregiving Skills - Dementia Care: https://shorturl.at/fLicY

Coursera: Living with Dementia: Impact on Individuals, Caregivers, Communities and Societies: https://shorturl.at/tg1yX

Demoer: Наръчник "Как да оказваме подкрепа на членове на семейството с деменция или Алцахаймер?": https://ec.europa.eu/programmes/erasmus-plus/project-result-content/8e214509-888b-410c-a140-72fb42fec5c4/DEMOER_IO1_-_BG.pdf

WKO: Резюмета на обучителни видеа за работа с дементно болни: https://www.wko.at/noe/gewerbe-handwerk/personenberatung-betreuung/15.-training-1-ko-rper-bul.pdf

Udemy: Dementia Care Training (12$): https://shorturl.at/2MlKr

Alzheimer's Association: Free Demetia & Alzheimer Modules: https://training.alz.org/

HealthCare Interactive: Online Dementia Care Training: https://hcinteractive.com/

Dementia Training Australia: Free courses: https://dta.com.au/

8.2. References and useful literature:

Алцхаймер Европа: https://www.alzheimer-europe.org/policy/national-dementia-strategies/bulgaria?language_content_entity=en

ДОКЛАД ВЪРХУ ДОБРИ ПРАКТИКИ В СФЕРАТА НА ГРИЖИ ЗА ХОРА С ДЕМЕНЦИЯ Изготвен за Фондация „Състрадание Алцхаймер България“ и Гражданско сдружение „Алцхаймер България“: https://shorturl.at/hj8WO

Национална стратегия за дългосрочна, URL: грижаhttps://www.strategy.bg/StrategicDocuments/View.aspx?lang=bg-BG&Id=882

Пилотно социологическо проучване на потребностите на хората с деменция и техните близки. Доклад. https://bgrf.org/uploads/docs/%D0%9F%D0%B8%D0%BB%D0%BE%D1%82%D0%BD%D0%BE%20%D1%81%D0%BE%D1%86%D0%B8%D0%BE%D0%BB%D0%BE%D0%B3%D0%B8%D1%87%D0%B5%D1%81%D0%BA%D0%BE%20%D0%BF%D1%80%D0%BE%D1%83%D1%87%D0%B2%D0%B0%D0%BD%D0%B5.pdf

Стратегически насоки за диагностика, превенция, лечение и грижи за хората с деменция в България, URL= http://www.dementia-bulgaria.com/downloads/strategy_231219.pdf

Сдружение Алцхаймер: https://alzheimer-bg.org/alzheimers/karta-na-speciliziranite-centrove-i-domove/

Фондация Състрадание Алцхаймер, URL: https://alzheimerbulgaria.org/%d0%be%d0%b1%d1%83%d1%87%d0%b5%d0%bd%d0%b8%d0%b5/

Building up caregiver skills to support people with dementia: https://talloiresnetwork.tufts.edu/blog/news/2024/08/29/building-up-caregiver-skills-to-support-people-with-dementia-in-bulgaria/

Dimitrov, I., Tzourio, C., Milanov, I., Deleva, N., & Traykov, L. (2012). Prevalence of dementia and mild cognitive impairment in a Bulgarian urban population. *American Journal of Alzheimer's Disease & Other Dementias®, 27*(2), 131–135. https://doi.org/10.1177/1533317512440490

Schmachtenberg, T., Monsees, J., & Thyrian, J. R. (2022). Structures for the care of people with dementia: A European comparison. *BMC Health Services Research, 22*, Article 1372. https://doi.org/10.1186/s12913-022-08715-7

Stoyan Stavru in Life with Dementia, Vox Nihili, https://soundcloud.com/discover

Larson, E.B. & Stroud, C. & Caregivers, Committee & Policy, Board & Services, Board & Division, Health & Medicine, National. (2021). Meeting the challenge of caring for persons living with dementia and their care partners and caregivers. 10.17226/26026.

Waddington, Claire & Zimmermann, Nikki & Crutch, Sebastian & Stott, Joshua & Brotherhood, Emilie & Support, Rare. (2023). Developing a psychoeducational programme for family caregivers of people living with late-stage dementia. Alzheimer's & Dementia. 19. 10.1002/alz.076154.

Crossing Boundaries: Integrating Formal and Informal Care for People with Dementia

Interviews Analysis

Petya Klimentova

Introduction

The following report analyses interviews in the sphere of dementia care in Bulgaria. Three are the types of respondents - managers of caregiving institutions in the country, dementia caregivers in institutions and family members – informal caregivers. The analysis is not representative. However, the text draws important suggestions and measures for improvement.

1. Social Services Managers

Seven people have been interviewed with questions regarding their involvement in dementia caregiving in Bulgaria. The primary focus is on the instruments used to support caregivers, the improvement of services, and ideas for education and integration of approaches to reduce stress, anxiety and risk of burnout among caregivers. The questionnaire is semi-structured, combining both open-ended and closed questions. In this way, a possibility is provided for securing the topic of the conversation while leaving enough space for personal involvement and considerations. All respondents work in residential institutions for long-term care. As a whole, they believe that above 50% of the personnel have been specially trained to work with people with dementia. The personnel are also trained in providing specialised care for people with dementia at least once per year or more frequently.

Both person-centred and routine-based approaches are being used in the institutions where our respondents work. Hence, plans for caring are being constantly or very frequently updated to support the best interests of the patient. As for therapeutic methods or activities, most respondents integrate cognitive stimulation, physiotherapy, music, art, or movement therapy. Less frequently, they support the healing process through the patients' memories. This shares a relatively wide variety of therapeutic tools used, especially as the expressive arts are cited so frequently.

It is promising that the institutions involve family members as active participants in the planning and communication about the personal patient program. However, several respondents do state that they either include family members regularly with limited participation or they do not include them at all.

How do residential care managers support the mental health and burnout prevention of their employees? Here, the answers are slightly different. However, regular supervision is seen as one of the most important forms of support for caregivers. Teambuilding, individual and group training are seen as another method of support. In some institutions, team members are encouraged to share their impressions and recommendations with the employer. However, none of the managers spoke of intervisions - peer consultations or reflective group practices where professionals meet to reflect on their practice, share experiences, and give each other feedback – usually without a formal supervisor. Managers also did not share any information about providing free digital tools for ongoing skills and knowledge improvement to their personnel. This suggests these methods are not accessible due to different reasons, such as financial resources or managers not prioritising this type of support.

Managers of social services give examples of good practices. We can draw a few obligatory interventions. Firstly, services must be person-centred. The level of patients' satisfaction with participation in the activities is most important. this is why managers try to organise monthly meetings with family members to create pleasant memories. Art therapy and music therapy appear important in strengthening the relationship between patients and caregivers. Music therapy is significantly improving the emotional well-being and vital tone of patients. Working with memories supports patients by providing attention to their personality, fighting the deconstruction of their mind and managing dementia symptoms, such as memory loss and disorientation.

Residential institutions for long-term care have integrated smart sensors, artificial intelligence and music. Not all respondents share information on how exactly they use such features to facilitate caregiving; only a few point out that they involve caregiving through online sessions. Although all respondents state they work closely with other institutions and professionals in caregiving for people with dementia, one of the biggest challenges remains a lack of personnel, training and financing. What help would they like to receive to improve dementia caregiving? The most frequent answer is support with training. This shows a high interest in leveraging the quality of skills, motivation and knowledge of the personnel. Another helpful support would be the improvement of the regulatory framework ("to be up-to-date for people with dementia"), as well as practical support and financing.

Conclusion

Most respondents in this group acknowledge the person-centred approach as the most effective way to care for patients with dementia. This inevitably reveals compassion and consciousness in the work as key factors for the patients' well-being. Social service managers show an intention to support their teams with an opportunity to develop knowledge and skills. However, most of the measures remain limited to supervision and some interest in the opinion of their employees. What seems problematic is the lack of practices such as intervisions, micro intervisions and cross-institutional intervisions, where employees can gather and lead the process of reflection within small, regular groups in a protected environment. These would help build empathy and collective knowledge while reducing isolation and stress levels. Digital tools are not effectively integrated into the care – neither for patients, nor for employees. Training through mobile apps – e.g. videos, quizzes and podcasts could support stress management, suggest new dementia care techniques, communication tools, and self-care strategies. None of the respondents mentioned platforms like Udemy, Coursera, Totara, EdApp, or even more widely used WhatsApp – all providing free and accessible tools. What is more important, managers show little interest in compassion for their employees. How caregivers overcome stress and fatigue remains their own job, in addition to caring for dementia patients. None of the respondents mentions structured programs for regular stress checks, nor emotional regulation or self-reflection. The use of art therapy and music therapy is promising. However, such approaches could be of use for caregivers if provided by professionals and organised by the management of the institutions as frequent and accessible approaches. Additionally, wellness Interventions, dedicated "recharge rooms" with calming music, and comfortable seating could help caregivers "gather their thoughts" and dissociate even for 10-15 minutes from the intensive work with patients. Another topic that we hypothesise might crystallise from the responses in the next section is the recognition, both material and moral, of the employees' hard work. Storytelling campaigns, both within caregivers and with other colleagues, could improve the sense of being valued and honoured. It could also increase employees' motivation and help them feel seen for who they are and protected in hard times of struggle with cases. This could be easily integrated through an internal website, newsletter or even offline gatherings. The absence of all these techniques in the managers' answers might also indicate that they need training in new methods of caring

for dementia patients and in taking care of the caregivers, and how this hard work might discourage and affect caregivers. On the other hand, it could also be that such a situation resonates from the lack of strict government recommendations for the need of strategic actions towards improving the caregivers' state.

2. Formal Caregivers

Questions in this section were targeted at caregivers, taking into account their education and competencies. The questionnaire was designed to take approximately 30 minutes, keeping respondents focused with open-ended questions. The aim was to identify good practices in dementia care, both for patients and caregivers. The roles of the respondents are as follows: nurses or health practitioners (7), therapists or psychologists (5), social workers or coordinators (4), social assistants (2), rehabilitators (2). Most of them work with various types of dementia and cannot point to a specific disease. Only a few work with vascular dementia or Alzheimer's. Most respondents have adopted a person-centred approach towards their patients, with some focusing more on medical care, while others keep the routine and daily tasks in focus. Just like with the managers of institutions, this shows a clear understanding of the need for individualised support for patients. On the other hand, as important as it might be for the patient's feelings of security and grounding, sticking to routines is also a key indicator of rigidity.

Therapy, support, music, arts, and verbal validation are seen as very important in caregivers' work, something which interviews with managers also reveal. In their work, caregivers integrate systems for video monitoring (i.e. detectors for falling onto the ground and cameras) and cognitive applications such as social or digital games. No matter how interactive, these options reveal a limited arsenal of tools for diversifying the work. However, caregivers believe they stimulate their patients cognitively every day.

Thirteen respondents decided to share good practices that work well in their facility. Person-centred care is the most important approach. The key focus is on minimising the level of anxiety, building stable communication and cooperation between the caregiver and the person, and promoting independence and autonomy. It means seeing the patient for who they are – "unique with their desires, habits and experiences"; "understanding to meet the needs of each user". Practices should integrate music therapy, arts and dance. They

acknowledge that within the tools they used, movement is key to success, as frequently patients are in an immobilised state. Additionally, conversations keep them occupied and overcome feelings of abandonment and loneliness. Another type of online therapy involves digital presentation of famous landmarks, museums and historical monuments. After each session, users prepare "feedback" in the form of a picture or application. However, sometimes patients need daily support in covering their basic needs, or involvement in cooking, flower-growing or painting. These answers reveal a picture where caregivers try to improve the state of their patients. They have incorporated music, arts and memory therapy, which are the most effective tools to fight dementia symptoms, especially memory loss, disorientation, feelings of isolation, despair and loneliness.

Most of the caregivers very often (every week) communicate with patients' relatives. However, some contact family members only once per month or even rarely, just in case or in an emergency. To improve communication, caregivers most frequently use regular phone calls or meetings. Less frequently, they include families in activities or sometimes write reports about how exactly they care for the patients. This suggests insufficient knowledge about the importance of family members and their inclusion in daily routines and therapeutic activities, or a lack of resources. Caregivers might feel obliged to fulfil a schedule and not have time to organise activities where they can include family members. But there are also other problems in the communication. Caregivers often feel that family members consider the responsibility for initiating contact is on the side of the caregiver. As caregivers, they would need more understanding, empathy and mutual respect. "Practice shows that the solution lies in building trust between employees and relatives". Relatives do not accept the severity of the disease. Another problem is that the caregiver is perceived as an employee who lacks a direct relationship with the family member. The immediate supervisor is obliged to do so. This might lead to misunderstanding, information being kept away from relatives, or inability to present to families the importance of the job done and the specifics of the case. Some caregivers think the situation might be improved if family members consult with a psychologist. How caregivers communicate is also seen as equally important. some believe the right approach is to give fewer explanations and direct any specific questions to the immediate superior, who is authorised to provide information. However, as we already discussed, this formal rule might

break the line of trust. Instead of giving specific details, referring to the supervisor might withhold important emotional data, often treasured by family members.

On the other hand, the formal rule might serve as a protective measure for caregivers, who often have to deal with aggression, provoked by deeper feelings of guilt in some relatives. This is why caregivers must work in a team with social workers and a psychiatrist. Relatives have different, sometimes unrealistic, expectations. Not accepting or understanding the condition as well as the patients' needs leads to delusions about what can and shall be done. Caregivers believe the solution is to keep family members on the loop of information about the daily, and sometimes (momentary) condition of the client. "Feedback is an important and integral part of the work, so that the client can be calm and properly cared for".

Caregivers are trained either once per year or several times per year. In this regard, they consider the most important skills for quality dementia care to be communication and empathy, stress management, care techniques, and teamwork.

Although caregivers acknowledge the importance of constant education, training and improving the way they care for people with dementia, the ideas they have for good dementia care practices are not new. It seems they once more highlight the approach of empathy, supporting patients' independence, providing a variety of activities, incorporating music therapy and including new types of therapies. One of the respondents cites a therapy also found as a good practice in our desk research – "monthly Art-cafe with the relatives of our users". The lack of information among the general audience is seen as equally important. One might think that government institutions should develop more awareness-building campaigns focused on increasing people's understanding of dementia and its consequences, as well as providing enough free tools to adapt to it and overcome the negative effects for the whole family.

> There should be more information in society about the nature of dementia and ways to care for such people. /Caregiver 3/

> Systematic work with families is necessary to obtain basic knowledge about dementia as well as practical skills in communicating with patients with dementia. /Caregiver 5/

> Training or mutual aid groups for relatives of those diagnosed with dementia. There should be more awareness because many of them do not understand the condition and needs of their relatives, and therefore, adequate care is not provided. / Caregiver 6/

There is a certain sense that “no one cares” about caregivers and people with dementia. Quality standards must be specified so that everyone, including caregivers, tries to meet them.

Conclusion

It seems that not only people with dementia, but also their caregivers, are left alone. Although interviewees mentioned trainings that take place once a year, or even several times a year, in general, skills for working and communicating with family members are not noticeable. On the other hand, caregivers themselves confirm that the involvement of family members is crucial for the well-being of patients[1]. Involving family members in the daily routines and activities of people living with dementia significantly improves the emotional and cognitive well-being of patients. Interactions with familiar people provide a sense of safety and reduce anxiety, while helping to preserve identity by stimulating long-term memories through shared conversations, photos or music. Family members often understand the communicative patterns and personal history, which supports more meaningful engagement with daily tasks and encourages motivation to participate in activities. Their participation ensures continuity between home and institutional care, strengthens orientation and contributes to preserving the dignity and autonomy of the person. Additionally, regular family involvement improves cooperation between caregivers and staff, leading to more personalised and effective care plans. Overall, the presence of loved ones supports the emotional stability, identity and social connection of patients with dementia, contributing to a better quality of life.

Furthermore, it is not clear to what extent the lack of direct contact between caregivers and family members supports the treatment process. Information shared during the interviews leads us to assume that the situation could be significantly improved if contact with loved ones were not isolated, but included at least one other team representative caring for the dementia patient. In this way, specialists could achieve greater trust in the team’s skills, comprehensive information, a more individualised approach to each case, and an understanding of the specifics.

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[1] The Role of Family Support in Dementia Care, the supportive care, https://www.thesupportivecare.com/blog/role-of-family-support-in-dementia-care

Lastly, there seems to be a need to develop diverse, widely accessible resources for dementia care. This includes both educational modules aimed at a broad audience, such as family, friends, community - to improve understanding of the severity of the disease and how to build an informal support network, and in a narrower sense - resources aimed at increasing and constantly improving and updating the skills of teams in dementia care institutions.

3. Family Member Caregivers

The questionnaire for family members who care for a person with dementia aimed to identify current practices in care and collect useful information for other caregivers. Most of the respondents are daughters. The majority are caring for their relatives for more than three years, with only a few caring for less than three years or even for just six months or less. The picture about who is the primary caregiver is colourful. Almost half of those questioned are the only caregivers. Others share responsibility or just support, or are rarely supported by someone else. Informal caregivers face various challenges. Caring for a family member with dementia often leads to significant emotional stress and burnout. The lack of information and direction about how to care is sufficient. However, physical exertion (e.g. fatigue, weightlifting) is also a challenge caregivers must overcome on their own. Unlike formal caregivers, family members stick more often to the routine. They find it the most effective strategy to care. Additionally, they integrate facilities and conversations as a method to ease the patient's condition. Hence, we suggest home-based informal caregivers either lack information about, or resources for incorporating more diverse care techniques, such as art, music, memories and movement therapy. This hypothesis is also supported by the fact that it is extremely hard for most respondents to find information, and they also don't know where to search. They believe that the most important ways to support the patient are through appropriate medical care and medication, social contacts and interaction, emotional support and a positive environment, as well as meaningful everyday interactions and activities. However, when it comes to success stories, practices or strategies, informal caregivers don't have quite to share. Many emphasise how important it is to organise structured activities, e.g. giving a task to sort colourful objects or participating in grooming routines like hair care and manicures. This provides a sense of familiarity and calms the patient. They acknowledge they must use a gentle tone, repeat information whenever necessary, and allow the person to feel useful through participation in daily tasks. These strategies reduce anxiety and build cooperation. A common and highly valued support is the use of daycare centres, such as those in Varna and Karnobat, operated by Alen Mak Med OOD. In these centres, patients receive professional care, psychological and medical support and engage in meaningful activities. The teams there build a reassuring environment. Their services are described as uplifting and transformative, both for patients and informal caregivers. Family members receive relief,

encouragement, and time to rest. We see these shared experiences as highlighting the value of community-based services, kindness, and person-centred care. It is then no surprise that our informal caregivers would appreciate most emotional support and consulting, help with daily chores, time for relaxing and more information and training,

The recommendations for other informal caregivers reveal a clear need for professional support and services to ease their everyday lives. All responses highlight the role of day care centres as a key resource that not only provides adequate care for people with dementia but also supports the mental and emotional health of their loved ones. All respondents emphasise that preserving one's own psyche is vital to being able to effectively care for the patient. In this regard, day care centres provide time for rest, the opportunity to work or time with family, which reduces the risk of burnout and depression. Almost all participants direct their recommendations towards the use of daycare centres that offer professional care, activities and a calm environment for both the sick and their loved ones. The service is perceived as a key buffer that delays the depletion of the personal resources of the caring family member. Long-term thinking is recommended, which includes planning for a possible deterioration of the condition and seeking adequate services in advance, including short-term accommodation and overnight groups. Not only is emotional resilience important, but also the timely upgrading of knowledge and skills that relatives need to acquire or receive through training and support.

The Alen Mak Day Care Centre in Varna is specially mentioned, which stands out for its high level of professionalism and attitude, which inspires trust and peace of mind in relatives.

4. General Conclusion

Several structural gaps emerge in our analysis. There are no integrated care pathways that formally connect the home environment, caregivers, and institutional settings. The results is negative for patients and families who experience disjointed care, discontinuity, and additional emotional strain. Although everyone speaks about the importance of more adequate proactive measures, we did not find any evidence for psychological screenings, regular burnout assessments, or early interventions targeting the mental health of professional or informal caregivers. The complete absence of peer support networks among caregivers, although it is low-cost and a high-impact measure, suggests a complete lack of information, motivation or finances for their implementation. Managers are described as showing "interest in employees' opinions", but there is no shared decision-making or participatory service design that would empower staff and support them to build their roles. Moreover, the lack of use of tools like WhatsApp, Coursera, or EdApp suggests digital illiteracy and exclusion among caregivers or management, and/or the absence of institutional support for tech adoption. The invisibility of caregivers' emotional needs points to a cultural minimisation of emotional labour, seeing care more as technical work, rather than deeply relational and psychologically taxing.

The responses of managers and formal and informal caregivers clearly emphasise that caring for people with dementia needs to be a shared responsibility. Otherwise, left alone, caregivers risk their own well-being. The best practice is a combination of professional service (day care centre) and emotional support, as well as awareness and advanced planning.

The third type of questionnaire once again emphasises the lack of awareness and access to resources. This is something that cannot be compensated for by the emotional attachment and desire to support loved ones.

The emphasis on the important role of day care centres suggests that the greatest resource should be directed towards developing more accessible and diverse care in them, as well as services aimed at involving family members in care activities. In addition, however, day care centres could be transformed into centres of emotional, informational and generally resource support with education and training for relatives of those affected by dementia.

This will expand the scope of their work, but will also ensure the building of trust with family members, the consolidation of the team of specialists who care for people with dementia, and the prevention of threats such as burnout and emotional exhaustion for families.

This all suggests that the situation could be significantly improved by launching a national or municipal-level digital platform where caregivers can access bite-sized training (microlearning), participate in forums, and download printable communication tools or therapeutic music playlists. Such a platform may also suggest more good practices and even drive for strategic change, like including dementia care modules in general healthcare and social work curricula, or training managers in “compassionate leadership”. Caregiver burnout should be recognised as a major risk. Managers may be the ones to lead the processes of fostering team trust, constructive feedback, and creating psychologically safe work environments. Another strategic change that could be led by the digital platform, alongside training and education modules, is proposing awards, financial incentives or a public storytelling space to dementia workers. This could be coordinated through national events or media campaigns. The conclusion is that what now consists of fragmented formal and informal care for people with dementia must be integrated. The road between home and institution must not be a road of exile for patients and feelings of blame for families. Rather, institutional care should be seen as a focal point for dementia care, while supporting caregivers and families and putting them at the centre of the caring system.

Mid-term Report

Field: **Adult Education**

Project Title: **DigiDementia: Developing digital practices for tackling dementia**

Project Acronym: **DigiDementia**

Project Start Date: **01/10/2024**

Project total: **24 months**

Project End Date: **30/09/2026**

Project lump sum: **250 000,00 €**

Country: **Czech Republic**

Organization Name:

Asociace poskytovatelů sociálních služeb České republiky, z.s.

Aliance pro telemedicínu a digitalizaci zdravotnictví a sociálních služeb, z.ú.

Executive Summary of Results

Dementia represents a growing health and social challenge in the Czech Republic, with the number of people affected expected to nearly double by 2050[1]. A significant step was the adoption of the *National Action Plan for Alzheimer's Disease and Other Similar Diseases 2020–2030*. In practice, however, challenges remain in coordinating care and ensuring the availability of services. Quality of life is sustained through a combination of health and social services, with a strong emphasis on enabling individuals to remain in their home environment for as long as possible. While caregivers and families often face demanding situations, best practices highlight the potential of individualised care, technological solutions, and support for community-based services.

The topic of digitalisation, acceptance, and the usability of technological innovations in dementia care represents an ongoing challenge that strongly resonates within the Czech context. While the Czech Republic is home to innovative projects in telemedicine and assistive robotics, their practical implementation is hindered by systemic issues such as the lack of standardised procedures, fragmented care, ethical dilemmas, and the absence of systematic training for caregivers in this field.

[1] https://radiozurnal.rozhlas.cz/pocet-lidi-s-demenci-se-muze-za-30-let-zdvojnasobit-otazka-prijeti-nemoci-je-8830542?utm_source

Current status of the dementia in the Czech Republic

In the Czech Republic, an estimated 171,000 people currently live with dementia, the majority of whom are women[2]. In the 80–85 age group, more than 10% of the population is affected by symptoms of dementia. By 2050, this number is expected to increase to approximately 297,000 individuals[3]. The main reason is the ageing population and increased life expectancy. **Dementia affects not only older adults but also their families, and it impacts the entire health and social care system.** According to demographic estimates, people with dementia in the Czech Republic affect the lives of another 250,000 individuals, whose quality of life is reduced due to the burden of caring for ill relatives. In the future, with global population ageing, the ratio between people with dementia and the working-age population is likely to change significantly. **While currently there are 3 people with dementia for every 100 working-age individuals (aged 15–64) in the Czech Republic, by 2050 this number could rise to 5–6.**

The occurrence of dementia should not be considered a normal part of ageing, but rather the result of disease, with all the associated implications, including the need for appropriate treatment, assistance, and support. Given the statistics above, it is clear that **financial resources allocated to the diagnosis, treatment, and especially the care of such affected individuals will need to increase significantly in the future.** Health care services, in particular, are currently unprepared for such a dramatic rise in the number of patients and face serious limitations in both care provision and treatment capacity.

The national strategy for addressing the situation is the *National Action Plan for Alzheimer's Disease and Other Similar Diseases 2020–2030*. The plan aims to improve diagnostics, service accessibility, and support for caregivers. **To overcome stigma and lack of awareness that may prevent people from seeking timely help, increasing public education and awareness about dementia is crucial.** The care for people with dementia is divided between the healthcare and social sectors, with social care prevailing in practice. However, **the system suffers from fragmentation and lacks a unified methodology across sectors.** People with dementia are treated by neurologists, psychiatrists, geriatricians, general practitioners, and other specialists, each following their own recommended procedures. These often overlap, leading to a lack of a unified vision for the optimal treatment of dementia patients. Efforts are underway to develop new guidelines that reflect the needs of people with dementia and their families. These guidelines aim to define the roles, competencies, and availability of different medical specialists; establish a clear system for diagnosis and treatment; determine reimbursement frameworks for individual procedures; and clarify prescribing responsibilities. A key objective of

[2] Česká alzheimerovská společnost. Výroční zpráva za rok 2023. Dostupné z <https://www.alzheimer.cz/cals/vyrocni-zpravy/>

[3] Ibid.

the new procedures is also to complete the network of services available to those in need. It is essential to ensure better integration between health and social care services and to enable personalised support for each person with dementia and their family.

The National Action Plan clearly emphasises that care procedures for people with dementia must be multidisciplinary and well-coordinated. These procedures focus not only on the individual with dementia but also on their caregiver, who often bears an excessive burden due to the fragmented nature of the care system, further complicating an already demanding role. In recent years, caregiver overload has become almost a “diagnosis” in its own right, with significant consequences for both caregivers and society at large.

General procedures for the diagnosis and treatment of people with dementia, as outlined in the National Action Plan:

- define the roles, competences, and availability of individual medical specialists;
- define the system of diagnosis and treatment;
- define the reimbursement framework for individual procedures and clarify prescribing options for relevant medications;
- support people with dementia and their caregivers throughout the entire course of the illness, with an emphasis on high-quality differential diagnosis and especially high-quality post-diagnostic support;
- pay attention to the impact of cognitive impairment on comorbidities and overall health.

In an ideal scenario, the system of care for people with dementia in the Czech Republic is organised hierarchically, integrating both health and social services. This is how care should function if effective interdisciplinary collaboration were in place:

- At the onset of symptoms, the person with dementia visits their general practitioner (GP), who initiates the diagnostic process and refers the patient for specialist assessments — typically to a neurologist, psychiatrist, or geriatrician. A diagnosis is then established, and treatment begins.
- Next, the patient is monitored by outpatient specialists: geriatric clinics, memory disorder centres, psychiatric clinics, counselling centres for families and caregivers. A major issue in the Czech Republic is the uneven regional availability of these services.
- In the later stages of dementia, it is ideal for the person to remain in their familiar environment for as long as possible, supported by both family and professional care. This includes mobile health services, such as home healthcare and home hospice care, as well as social services like in-home care, personal assistance, and respite care.
- When it is no longer possible for the person with dementia to remain at home, even with support, and when healthcare services are not indicated, it becomes necessary to utilise residential social care for older adults, dementia care units and respite residential services.

- For care to be truly comprehensive, support must also be provided to caregivers, family members, and close relatives. The illness of a loved one can have serious impacts on these groups. As the disease progresses, supporting family members becomes increasingly important through education and psychological support for caregivers, self-help groups, and counselling services (e.g., the Czech Alzheimer Society). Coordination of care is essential. The role of care coordinator is fulfilled by a social worker, who plays a key role in linking healthcare and social services. Care coordination must be based on an individual plan tailored to the needs of the client and their family.

As part of the DigiDementia project, in-depth interviews and an online survey were conducted in May 2025, focusing on key topics in dementia care. These included fundamental principles and approaches to care, caregiver qualifications and training, the involvement of family members, innovations and technologies, and broader challenges in the field.

In-depth interviews (conducted both face-to-face and online) were carried out with a total of 11 individuals: two professional caregivers, two family members, and seven representatives of social services management. Interviews with the two caregivers revealed that a patient and empathetic approach, activation through music and reminiscence, and cooperation with families prove effective in practice. The caregivers also highlighted issues such as **staff shortages, difficulty ensuring client safety, and chronic overload.** Interviews with the two family members emphasised the importance of keeping the person with dementia in their home environment, using available technologies and utilising services provided by organisations that support home-based care. A researcher from the APSS ČR also conducted five in-depth interviews with the managers of social services providing care to clients with dementia. These interviews showed that **while managers strive to emphasise individualised and client-centred care, their main challenge is the lack of qualified personnel.** Two additional in-depth interviews with managers were carried out by a researcher from the ATDZ. These interviews pointed to the staff's commitment to providing quality care, but also to the need for systemic changes and better funding to ensure adequate care for the growing number of people with dementia. The main challenges identified were staff shortages and high turnover. There is an emphasis on the need to improve working conditions and salary scales for staff. Additionally, there is a need to strengthen outreach services to reduce pressure on residential facilities. In recent years, facilities have been focusing on the use and implementation of digital tools and technologies, such as fall detection systems, relaxation chairs and tools that help people with dementia with orientation.

The findings above were confirmed by an online survey conducted among professional caregivers and social service management. For participation in the survey, 10 residential care homes for people with dementia from various regions of the Czech Republic were specifically approached. The survey of professional caregivers included 30 respondents, while the

questionnaire for management was completed by 5 respondents. The survey highlighted several key trends and issues:

- In the Czech Republic, an individualised approach to dementia care prevails: 96,7% of professional caregiver respondents stated that they create a care plan for each client based on their individual needs and update it regularly. This was also confirmed by managers' representatives, 60% of whom stated that the plan is updated based on changing needs, and 40% update it monthly.
- The most commonly used approaches include reminiscence therapy (46,7%) and music therapy (43,3%), as well as basal stimulation and animal-assisted activities.
- Technology is used to a limited extent - only a minority of respondents (43,3%) reported regular use of applications, virtual reality or therapeutic tools.
- Cooperation with families is frequent but can also be problematic, particularly due to unrealistic expectations and a lack of understanding of dementia as a systemic disease. Regular contact with clients' families at least once a week was reported by 30% of respondents, while 46,7% stated that they communicate with families only when needed or in crises.
- An interesting finding came from the question of methods for improving communication with family members of people with dementia. Seven respondents (23,3%) admitted they have no systematic approach. They could be inspired by others who reported successfully using regular meetings, telephone consultations, or involving families in client activities. Some residential homes organise joint therapeutic activities such as sports games or social therapy workshops.
- The good news is that professional caregivers frequently participate in specialised training focused on dementia care. According to the survey, 40% attend such training once a year and 43,3% several times a year. 100% of managers confirmed that they offer such courses to staff at least annually or more frequently. The training focuses, for example, on communication with people with dementia and handling challenging situations. Caregivers also have access to external psychological services and relaxation techniques to prevent burnout.
- The biggest challenges include: staff shortages, low qualification levels, funding issues and lack of systemic support.

The results show that although there are effective approaches and examples of good practice in dementia care in the Czech Republic, systematic support and capacity building are lacking, both of which are essential for ensuring long-term, high-quality, dignified and sustainable care.

Best practices in the Czech Republic

Based on in-depth interviews with professional caregivers, family members of people with dementia, and managers of social service providers, several recurring approaches can be identified in Czech practice that represent examples of good practice in care. These approaches are grounded in everyday experience and reflect both the needs of those involved and the systemic limitations they face.

1. Individualised approach and respect for people with dementia

Caregivers repeatedly emphasised the importance of individualised care and adapting to the daily condition of the client with dementia:

"We take an individual approach; we treat each person differently. (...) We try to make sure they understand everything that's happening, based on their condition, and we keep talking to them." (Caregiver 2)

"I have individual care plans in place. But still, you have to care and respond according to the current situation - clients change every day..." (Caregiver 1)

Managers reflected this approach as well, for example:

"We base our care on the principles of individualised approach, dignity, safety, and support of the client's remaining abilities. We try to tailor care as much as possible to each person's needs, considering their life story and personal preferences. Unfortunately, some clients have a form of dementia that makes activation and engagement very difficult." (Manager 3)

"We focus on respect, patience and an individualised approach. Every client is different, and we try to adapt to them, not the other way around. The main goal is to create a safe, calm, and friendly environment where people feel accepted." (Manager 4)

2. Emphasis on quality of life

One of the approaches that has proven effective in practice is focusing on quality of life rather than strict control:

"The client is allowed everything (cake even if they're diabetic, a glass of beer...). We try to improve their quality of life." (Caregiver 2)

"We try to eliminate all institutional and regimented forms of care. Sometimes it's a challenge, because such systems are still ingrained to some extent in the mindset of caregivers. This includes things like serving food, providing hygiene care, etc. We aim to remove any rigid routines and meet needs as they arise." (Manager 1)

3. The importance of the home environment and preserving rituals

Informal caregivers (family members) repeatedly emphasised the importance of maintaining a familiar environment:

"I think the main thing is for the person with dementia to stay oriented in their home environment." (Family Member 1)

"Together with the nurses, we try to make sure Mom keeps doing the things she's always loved - going for walks, knitting, cleaning…" (Family Member 1)

The importance of this approach was also highlighted by managers:

"We consider the introduction of a so-called 'living memory library' a best practice, where clients share life stories through photographs and personal objects. This method strengthened relationships between clients and staff and helped improve orientation within the environment." (Manager 2)

"In practice, we encounter limitations due to staff workload, but we try to ensure that each client has their familiar routines, objects, and activities that provide a sense of security." (Manager 3)

4. Activation through meaningful stimuli

The most frequently mentioned activities include singing, working with memories, the presence of animals and interaction with children:

"They respond best to songs." (Caregiver 1)

"Students from the nearby school come to put on a program. Then a lady comes with dogs - that's great." (Caregiver 2)

"I've noticed that Grandma goes once a week to sing with an accordion player (...) they also have animals - budgies, cats, hamsters." (Family Member 2)

"We most commonly use reminiscence activities, listening to familiar music, fine motor activities, aromatherapy and shared rituals. Animal-assisted activities and simple forms of multisensory stimulation also receive positive feedback and are feasible in our organisation." (Manager 3)

Activation through meaningful stimuli was also cited by respondents in the questionnaire survey. When asked about proven examples of good practice in the care of older adults with dementia, they replied:

- *"supporting independence, communication, non-verbal communication, empathy"*
- *"conversations, naming daily-used items, greeting by name, reminding, showing, letting clients make decisions, motivating"*
- *"talking to them a lot - and with the families too"*

5. Support through technology and environment

Respondents mentioned the use of tablets, camera systems, pressure sensors and architectural elements designed to reduce disorientation:

"We've had tablets for the past year, showing videos with films, and clients can also play cards on them." (Caregiver 1)

"We've set up the hallways here to reduce the feeling of getting lost - it's done in a way that the exit doors are covered with wallpaper that looks like bookshelves." (Caregiver 2)

"I bought my mom a tablet, and when we're together, we play games and solve Sudoku puzzles." (Family Member 1)

"At the moment, we're mostly looking for technologies that would be useful for us. We like the idea of using virtual reality headsets with programs tailored to each client. For example, for a man who used to work as a bus driver, we tried a virtual visit to a public transport museum." (Manager 1)

"We use mobile apps to monitor clients' daily routines, cognitive training via tablets, orientation and communication tools with QR codes, and GPS technologies to prevent disorientation among mobile clients." (Manager 2)

"Our 'digital memory zone' works very well - it's a space with a touchscreen where clients can view photos, videos, or music from their past. It's often the key to helping a client open up again or smile. Although recently, this activity is only suitable for a limited number of clients. Some are no longer able to engage with it." (Manager 4)

6. Emotional and physical support as the foundation of care

"We try to talk to clients all the time, even if they may not respond. Whenever we do anything, we explain it to them and talk to them. We sing with them a lot, we touch them gently - physical contact is important too. In our facility, we've agreed with families that we can use clients' first names." (Caregiver 1)

"Speak in a calm, kind voice. Above all, visit and spend time with Grandma. Once staying at home was no longer possible, it was important that she didn't feel lonely or abandoned." (Family Member 2)

"We mainly monitor clients' behaviour and mood - whether they've calmed down, whether they're engaging, whether their reactions are positive. We do have a system of records and observations, but what tells us the most is daily contact and feedback from staff." (Manager 4)

Support must be provided not only to clients but also to professional caregivers. Managers described this, for example, as follows:

"We offer the option of supervision, try to create a stable work environment and accommodate schedules. However, due to workload, it's difficult to find time and space for deeper support, which we consider a major weakness of the system." (Manager 3)

"We offer regular supervision, access to anonymous psychological support, support for work-life balance (e.g. flexible shifts), and organise relaxation programs. We appreciate our staff's work and try to build a team culture based on respect. It's not always easy, but we strive to create a friendly, cooperative team." (Manager 2)

"We've set up options for supervision and peer review. As part of the bonuses, we contribute to holidays and wellness programs. I think we have an above-standard internal communication system - we try to talk to staff a lot and resolve issues before they arise." (Manager 1)

7. The importance of cooperation with family and community

"It's great when the family cooperates and gets involved in the care - that's really ideal. We even have a lady with dementia here whose husband takes care of her, and we made it possible for them to live together. I think that's a good practice." (Caregiver 1)

"Reach out to social workers in your area. Don't hesitate to visit facilities that have experience with dementia care, even before it becomes necessary. They really are knowledgeable in this field and can advise you. Visit the facilities early." (Family Member 2)

"We have an open-door policy for families, and they can also take part in informal meetings of everyone involved in care. We meet once a month over coffee and have discussions. These meetings are often attended by relatives who had loved ones here in the past. I must say, though, that not all family members want to get involved in care." (Manager 1)

"We invite families to collaborate in creating biographical profiles and individual care plans. Unfortunately, only a small portion of them actually participate. We try to motivate them to visit, communicate and share information, but we often encounter low interest or exhaustion on the part of the families." (Manager 3)

"We try to involve families from the beginning - during admission, when developing the biography and on an ongoing basis. Unfortunately, I must say that some families are not very cooperative. Instead of working together, we get criticism or tension, which is unfortunate - because in the end, it's the clients who suffer the most." (Manager 4)

Limits, gaps, and barriers in the status of dementia in the Czech Republic

The topic of digitalisation, acceptance and usability of technological innovations in dementia care presents a current challenge that strongly resonates within the Czech context. The issue was explored in more detail by a researcher from ATDZ as part of their desk research. Their findings highlight practical obstacles that hinder further development in this area.

Adapting to digital systems poses a major challenge, particularly due to the specific needs of individuals with cognitive impairments. Applications such as "*Memorica"*, developed in the Czech Republic for memory training, or sensor wristbands that monitor patient safety, offer potential but face practical limitations in effective use. A study conducted by the University Hospital in Olomouc (2023) found that even after three months of training, 40% of patients with mild dementia still had difficulty using tablets. A key issue is the lack of systematic training for caregivers - projects like the "*TechSenior*" (Prag) are still rare. A possible solution could be an intuitive design that minimises the need for reading, such as the "*DemensCare*" app from the University of Economics in Prague, which uses voice navigation and visual icons. Pilot testing in facilities like Domov Slunečnice in Brno suggests that collaboration between developers and social service institutions increases the acceptance of technologies.

The lack of standardised procedures complicates the integration of digital tools into the Czech healthcare and social systems. Unlike countries such as Germany, which has a standardised national dementia plan, diagnosis and treatment in the Czech Republic follow informal guidelines issued by individual clinics and specialised facilities. Moreover, the digitalisation of health records (eHealth system) lacks modules for tracking dementia progression, limiting the

potential of projects such as "*DemenCALL"* (Ústí Region), which are unable to work with unified data. Experts, therefore propose the establishment of a National Dementia Task Force under the Ministry of Health, bringing together neurologists, IT specialists and representatives from social service providers. European standards like "*EuroDem"*, which define criteria for digital therapies, could serve as inspiration.

Barriers to the adoption of technology in practice are mainly linked to the low digital literacy of older adults and a general mistrust of new solutions. According to the Czech Statistical Office (2023), 68% of Czechs over the age of 70 have never used a health-related app, most often due to fear of incorrect use (52%) or lack of internet access in rural areas (23%). While initiatives like "*Tablets for Seniors"* (by the Ministry of Labour and Social Affairs) distribute preconfigured devices, they do not address the specific needs of people with dementia. More successful are local initiatives, such as the "*Digital Assistants"* program in the Karlovy Vary Region, where volunteers teach older adults how to use digital technologies through individual lessons. However, systemic change requires greater state support - for example, subsidies for purchasing devices for low-income families or educational media campaigns, such as the "*Silver Clicking"* show on Czech Television.

Another systemic issue is the fragmentation of care. Social services providers, healthcare institutions and outpatient specialists often operate in isolation, which prevents the effective use of technologies. For example, data from smartwatches is not integrated into medical records, limiting its diagnostic potential. A positive exception is the "*Integrated DemenCE Center"* (Ostrava), which connects neurologists, psychologists and professional caregivers through a shared digital platform. Similarly, the "*Shared Care"* project in the South Moravian Region uses a cloud-based system to coordinate medication and activities. However, legislation remains a major barrier - the Social Services Act (No. 108/2006 Coll.) still does not address the interoperability of digital systems across sectors.

Ethical dilemmas are also being discussed, especially those related to technologies that infringe on privacy. For instance, the use of GPS trackers in residential care homes raises questions such as: Is it ethical to monitor individuals with orientation disorders without their explicit consent? Similarly controversial are AI tools that analyse speech or movement, such as the "*CogniCheck"* system, which may reduce human contact in the diagnostic process. In response, Palacký University in Olomouc developed an Ethical Code for Digital Assistive Technologies (DATs) in 2024, emphasising the right of individuals to "digital abstinence" and the importance of transparent data collection. This document could serve as a foundation for national regulation.

The positive impacts of digital technologies, however, are indisputable. A study by Masaryk University (2024) demonstrated that virtual reality (e.g. virtual walks through Prague) reduced anxiety in 60% of patients with dementia. The "*Reminiscence"* app by CZ.NIC, which creates

digital albums of family photographs, enhances verbal communication in individuals in the early stages of the disease. The economic benefits are also evident - an analysis by the Ministry of Labour and Social Affairs (MPSV, 2025) showed that assistive robots such as "*Pepper",* used in a care home in Hradec Králové, reduced care costs by 15% through automation of routine tasks. Looking ahead, "*smart apartments*" equipped with IoT devices (e.g. in Plzeň) are being tested, which automatically adjust lighting or temperature according to the needs of people with dementia.

Although the Czech Republic has innovative projects such as telemedicine and assistive robotics, their full potential is hindered by systemic shortcomings. Key priorities should include the creation of a national registry of digital interventions to assess their effectiveness, support for interdisciplinary collaboration (across healthcare, IT and municipalities) and tax incentives for companies developing technologies for older adults. An inspiration could be the Austrian "*DigiDemenz"* model, where the state covers 80% of technology costs for families caring for people with dementia. Without these steps, the Czech Republic will remain more of a passive recipient than an active innovator in the field of digital dementia care.

Conclusions and recommendations

Available data and field reports indicate that the Czech Republic is facing a growing challenge related to dementia, not only due to capacity and systemic shortcomings, but also because of the evolving needs of people with dementia and their families. Nevertheless, there are numerous examples of good practice that can be further developed and supported.

Conclusions:

- The number of people with dementia in the Czech Republic is expected to grow significantly, while the system is not adequately prepared to provide care or support for caregivers.
- A key factor in quality of life is the ability to remain in the home environment for as long as possible, supported by technology and community services.
- In practice, a unified system of care coordination is lacking - care is often fragmented across different specialities and institutions.
- Caregivers (both professional and family members) need not only professional support but also psychological resources and respite services.
- Client activation works best when it is based on emotions, memories and personal relationships.
- Staffing is a major weakness - there is a shortage not only in numbers but also in specialisation, particularly of occupational therapists, psychologists, speech therapists and geriatricians.
- Approaches to dementia care across facilities are becoming increasingly aligned, regardless of service type (e.g. care home vs. specialised care home) - with a strong emphasis on individualised work, humanity and the elimination of institutional practices.

Recommendations:

- Support the development of community-based and home care, including outreach services and the availability of general practitioners for home visits.
- Introduce a standardised, interdisciplinary, coordinated approach to the diagnosis, treatment and follow-up care of people with dementia.
- Strengthen training for caregivers, with a focus on managing challenging behaviours, preventing burnout and ensuring ethical care.

- Promote the use of validated digital tools (e.g. Cognifit, CarePredict) that can enhance safety, stimulation and access to information.
- Encourage inter-institutional cooperation and awareness-raising, including the involvement of schools, volunteers and families.
- Ensure financial stability and expand the network of services, including residential home care, to relieve the burden on family caregivers.

An overview of digital tools and digital solutions for dementia care is also an integral part of this report. This overview can be found in Annex 1.

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Annexes

Annex 1: Digital Tools and Technologies for Dementia Detection and Care in the Czech Republic

Digital Tools and Technologies for Dementia Detection and Care in the Czech Republic

(alphabetically sorted)

AI-Mind

Function:

- Analyses EEG data to identify patterns of brain activity that may indicate dementia risk.
- Uses machine learning to process and interpret data, allowing for accurate cognitive health assessments.
- Offers tools for physicians to support early diagnosis and monitor cognitive disorder progression.

Use:

- Enables early identification of cognitive problems, leading to better treatment management and planning.
- Supports clinical research projects focused on dementia.
- Assists doctors in planning and evaluating treatment strategies for patients with dementia.

AngelSense

Function:

- A platform designed to support caregivers of loved ones who may get lost or require additional monitoring.
- Real-time GPS tracking enables caregivers to monitor the person's location, which is useful if they become lost or move outside a safe zone.
- Allows geofencing - setting safe zones and receiving alerts when the person leaves them.
- Enables two-way communication.
- Allows monitoring of movement patterns, which can help understand client behaviour and routines.

Use:

- The platform's overall goal is to enhance the safety of clients with various needs and provide caregivers with peace of mind and support.

Assistance Unit for Patients with Alzheimer's Disease

Function:

- A platform designed to support patients suffering from Alzheimer's disease and their caregivers.
- Provides caregivers with essential information about Alzheimer's, including symptoms, treatment, and care strategies, helping families and caregivers better understand the condition.

- Offers access to tools and resources that help caregivers care more effectively for patients, including techniques for managing behavioural and emotional needs.
- Includes cognitive training activities and games that stimulate memory and thinking, helping to maintain cognitive abilities.
- Supports better communication between patients and their families or caregivers.
- Enables planning and organising of various activities and therapeutic programs that help patients maintain an active lifestyle.

Use:

- The platform's goal is to improve the quality of life for people with Alzheimer's disease and to ease the care and support provided by their loved ones.

Assistive Robot Pepper

Function:

- A humanoid robot deployed in a senior care home in Hradec Králové:
- Task reminders (e.g. timely medication alerts).
- Conduct simple conversations, reads news, plays music.
- Detects falls or unusual inactivity.

Use:

- According to a report by the Ministry of Labour and Social Affairs (2025), the robot reduced staff workload by 20% and increased patient participation in group activities.
- Its high acquisition cost (approx. CZK 300,000) currently limits large-scale adoption.

CarePredict – AI

Function:

- A platform using artificial intelligence (AI) to monitor and analyse the behaviour of seniors and people in need of care.
- Utilizes wearable devices and sensors to monitor users' daily activities such as movement, sleep and other routines.
- The AI analyses behavioural patterns and detects any unusual changes that may signal health problems (e.g. if a patient starts walking less or alters sleeping habits).
- Sends alerts to caregivers and families when changes are detected, allowing timely response to potential health issues.

Use:

- CarePredict can improve the quality of life for seniors and people requiring care and support caregivers in providing effective and proactive care.

CaringBridge

Function:

- Provides a platform for creating personal websites to share health updates and stories.
- Allows users to share photos, updates, and communicate with family and friends.
- Simplifies the process of sharing information with all involved parties.

Use:

- Helps families and caregivers effectively share health-related updates about people with dementia.
- Keeps loved ones informed without the need to repeatedly share the same information.
- Fosters a sense of connection and support during difficult times, which is essential for everyone's emotional well-being.

CLARA

Function:

- Facilitates recruitment, management, and tracking of clinical trials through automation and data analytics.
- Provides a platform for efficient study administration, ensuring regulatory compliance and process optimization.
- Enables monitoring and analysis of study results, helping accelerate the development of new therapeutics.

Use:

- Enables effective management of dementia-focused clinical trials, contributing to the development of new treatments.
- Assists researchers and pharmaceutical companies in optimizing studies and improving data quality.
- Serves as a key tool for faster implementation of research findings into clinical practice.

Cogni Trainee

Function:

- Designed to support cognitive training and rehabilitation, especially for older adults or those with cognitive impairments.
- Offers a variety of exercises and activities focused on training memory, attention, logical thinking, and other cognitive functions.
- Also suitable for people recovering from neurological conditions (e.g. stroke, brain injuries) who need systematic training to regain cognitive skills.
- Enables individualized training plans.
- Includes interactive and engaging activities to motivate users and maintain interest in training and development.

Use:

- Cogni Trainee supports cognitive skill improvement and enhances quality of life for users who wish to improve and maintain their mental abilities (it can also serve a preventive function).

CogniCheck
Function:
- An AI tool developed by a Czech startup to analyse speech and movement patterns:
- Detects changes in speech: slowed tempo, word repetition, syntax errors.
- Assesses motor function via camera (e.g. hand tremors, gait instability).

Use:
- Used in neurology outpatient clinics (e.g. Motol University Hospital) for early diagnosis of dementia.
- Some physicians note that automated diagnosis may undermine personal contact with the patient.

Cognifit
Function:
- The app offers tests focused on various cognitive domains such as memory, attention, perception, coordination and executive function. These tests help users monitor their cognitive health and identify areas that may need improvement.
- Based on the assessment results, the app creates personalized training plans aimed at strengthening specific cognitive abilities. Training programs include a variety of games and exercises designed to be both fun and effective.
- Users can monitor their progress through a scoring system that reflects their performance in different cognitive domains. The app also provides an estimate of cognitive age, which can be motivating for continued training.

Use:
- Regular use of the app can help detect early signs of cognitive decline, which is key for timely intervention.
- While it does not replace professional therapy, it can serve as a supplementary tool for stimulating cognitive skills in individuals with mild to moderate dementia.
- Caregivers can use the app to better understand their loved one's cognitive condition and plan appropriate activities.

DemenCALL (Ústí nad Labem):
- A telemedicine platform for remote consultations with neurologists.
- Patients wear EKG and oximetry sensors.
- Data is transmitted in real time.

DemensCare
Function:
- The application developed by the University of Economics in Prague (VŠE) is designed for intuitive use, taking into account limited digital literacy:
- Voice navigation in Czech.

- Visual icons instead of text (e.g. a phone symbol for contacting a caregiver).
- Automatic reminders for important tasks (e.g. taking medication, staying hydrated).

Use:

- Tested at the *Domov Slunečnice* care home in Brno, where clients with dementia use it for basic communication with staff.
- Integrates with smartwatches to monitor physiological parameters (e.g. heart rate, sleep).

FallSafe

Function:

- Wearable sensors that detect falls and immediately alert caregivers or family members.
- Offers an app for movement tracking and fall risk analysis.
- Provides data for planning preventive measures.

Use:

- Fall prevention is crucial for the safety of people with dementia, who may have impaired balance or coordination.
- Enables rapid response in the event of a fall, minimizing the risk of serious injury.
- Gives peace of mind to families and caregivers by ensuring continuous monitoring and safety protocols.

FiveLives App

Function:

- The app offers tests and dementia risk assessments to help users identify potential cognitive issues.
- Based on the results, it provides personalized lifestyle recommendations that may reduce the risk of cognitive decline.
- Users can track their scores and progress in improving cognitive health.

Use:

- Helps identify early signs of cognitive decline for timely intervention.
- Serves as a preventive tool for middle-aged individuals seeking to reduce dementia risk.
- Provides useful insights for caregivers to plan activities for people with dementia.

GPS SmartSole

Function:

- A monitoring device embedded in shoe insoles that uses GPS technology to track the wearer’s location.
- Sends alerts if the wearer leaves a pre-set safety zone, enabling quick response.
- The system is managed via an app that allows real-time tracking.

Use:

- Enables families and caregivers to monitor the movements of individuals with dementia, ensuring their safety and reducing the risk of disorientation.
- Provides peace of mind by allowing fast action in the event of an unplanned departure from home.
- It is discreet and non-invasive, ideal for individuals who might reject other tracking devices.

IoT Smart Apartments (Plzeň)

Function:

- A network of interconnected devices in test apartments for seniors.
- Automatic environmental adjustments, such as dimming lights during evening restlessness or temperature regulation.
- Detection of water leaks and alerts for forgotten stoves.
- Notifications to caregivers about changes in routine (e.g. the patient hasn't eaten at their usual time).

Use:

- A pilot project in Plzeň showed a 35% reduction in household accidents.
- Expansion to 50 apartments is planned under the *"Smart Aging"* program by the Ministry of Labour and Social Affairs.

Lumosity

Function:

- Offers over 50 games targeting various cognitive skills, such as memory, attention, processing speed, cognitive flexibility, and problem-solving.
- Based on an initial test, the app customizes a training plan tailored to the user's individual needs, with game difficulty dynamically adjusting based on performance.
- Users are encouraged to practice regularly through daily challenges and progress tracking.

Use:

- Promotes its games as research-based and collaborates with over 40 university researchers worldwide.
- A popular tool for cognitive training, useful for maintaining mental activity.
- However, its effectiveness in preventing or treating cognitive disorders has not been conclusively proven.

Medisafe

Function:

- Allows users (typically caregivers in later stages of dementia) to set reminders for medication intake, ensuring correct timing and dosage.
- Additional features are primarily intended for caregivers:
    - Track medication schedules and record when doses are taken, easing treatment management and tracking.

- Share medication information with family or caregivers, offering added support and oversight.
- Provides information about potential drug interactions and alerts to possible issues, enhancing medication safety.

Use:

- Contains medication-related content including instructions, side effects and other essential information to help users understand their treatment, primarily for caregivers.
- A tool that simplifies medication management and supports adherence to treatment plans, which is essential for effective healthcare.

Memorica

Function:

- An application developed by a team of Czech neurologists and programmers that combines cognitive training games focused on memory, attention and spatial orientation.

Modules:

- Memory card game (*pexeso*) with personalised images (e.g. family photographs).
- Timelines for training sequential memory (e.g. organising daily events).
- Word tasks with difficulty levels adapted to the stage of dementia.

Use:

- Used in outpatient centres (e.g. in Prague and Brno) as a supplement to therapy.
- Caregivers can monitor user progress through an analytical dashboard.
- A 2024 study showed a 30% slowdown in cognitive decline among users after six months of regular use.

MemoryLane

Function:

- Enables the creation and sharing of digital memory albums in the form of stories, photos, and videos.
- Includes interactive features that make it easy for users to view and share memories.
- Allows for the preservation of important life stories and personal history.

Use:

- Helps stimulate memory and encourages conversation between the person with dementia and their loved ones.
- Serves as a therapeutic tool to preserve personal identity and life history.
- Facilitates intergenerational interaction, which can enrich and strengthen relationships.

NeuroFlex

Function:

- Measures and analyses brain activity and cognitive function - useful for performance monitoring and rehabilitation.
- Provides tools for tracking and optimizing cognitive performance, with personalized adjustments.
- Allows comparisons across cognitive domains and tracks improvement.

Use:

- Helps monitor progress and improvement in cognitive abilities in people with dementia.
- Serves as a rehabilitation tool for improving brain function after injury.
- Supplies data for planning and optimizing therapeutic programs.

PARO

Function:

- PARO is a therapeutic robot shaped like a seal that responds to touch, sound, and light, mimicking the behaviour of a real animal.
- Provides emotional support and stimulation through interactive functions.
- Creates a sense of calm and joy through realistic movements and sounds.

Use:

- Helps reduce stress, anxiety, and loneliness in people with dementia.
- Used in senior homes and hospitals as part of therapeutic sessions.
- Promotes emotional well-being and interaction, which can be especially valuable for individuals with limited social contact.

RemindMecare

Function:

- Designed to support care for seniors, especially those with dementia or other cognitive challenges.
- Enables caregivers to better understand individual needs and preferences, allowing for personalised care.
- Offers various games and activities that help stimulate memory and cognitive abilities, supporting mental engagement and enjoyment.
- Allows for tracking progress and changes in behaviour or health status, which can be crucial for early identification of potential problems or needs.
- Facilitates communication between users, caregivers and family members, helping maintain social bonds and support.

Use:

- The platform aims to improve the quality of life for individuals with cognitive impairments through technology and personalised care.

Reminiscence (CZ.NIC)

Function:

- A digital platform for reminiscence therapy
- Allows uploading of family photos, videos or audio recordings into a personal album.

- AI-powered automatic tagging (e.g. recognizing locations or people in photos).
- Interactive timeline to visualize life stages.

Use:

- Used in the care of people with early-stage Alzheimer's disease.
- In care homes (e.g. in Olomouc), it is used for group activities - shared viewing of albums sparks discussion and strengthens social bonds.

TechSenior (Prague):

- Training program for caregivers focused on using technology.
- Courses cover working with apps, setting up GPS trackers and troubleshooting common issues.

Tolion Digital Health Coach

Function:

- Provides personalised health recommendations based on data from wearable devices such as smartwatches. The app analyses information on exercise, nutrition, sleep and stress.
- Offers individualised plans to improve health and well-being, tailored to the user's specific needs and goals.
- Users can track their progress through clear graphs and statistics, enabling better management of their health.

Use:

- Supports the management of a healthy lifestyle for people with dementia, which can positively impact their overall well-being.
- Provides caregivers with tools to monitor health indicators of their loved ones and offers guidance for improving cognitive health.

Virtual Reality (VR Therapy)

Function:

- Immersive scene projection (e.g. walks through Prague, virtual garden) via Oculus Quest 3 headsets.
- Dementia patients can "visit" places from their youth (e.g. childhood streets).
- Activities include collecting virtual flowers, communicating with avatars.

Use:

- A study by Masaryk University (2024) showed a reduction in anxiety and apathy in 60% of users.
- Used in day care centres (e.g., in Liberec) 2–3 times a week in 30-minute sessions.
- Offers a high degree of personalisation and interactivity.

Mid-term Report

Field: **Adult Education**

Project Title: **DigiDementia: Developing digital practices for tackling dementia**

Project Acronym: **DigiDementia**

Project Start Date: **01/10/2024**

Project total: **24 months**

Project End Date: **30/09/2026**

Project lump sum: **250 000,00 €**

Country: **Greece**

Organization Name: **Metropolitan College, AKTIOS**

Executive Summary of Results

This desk research report for the DigiDementia project examines the current state, challenges, and best practices in dementia care in Greece, with a special focus on digital tools and support structures. Dementia affects over 200,000 people in Greece, with an increasing burden projected for the coming decades. The National Dementia Strategy, supported by various NGOs like the Athens Alzheimer Association, has laid groundwork in memory clinics, day care centers, home support, and caregiver education. However, service gaps persist—especially in rural areas—and heavy reliance on informal caregivers remains a challenge.

The report draws on both desk research and field interviews to highlight innovative approaches such as tele-support services, home-based interventions, digital literacy workshops, and culturally adapted e-learning tools like iSupport. Field data emphasizes the importance of routine, person-centered care, social engagement, and caregiver support. Creative therapies and digital technologies are increasingly being used to enhance cognitive stimulation and care coordination.

Overall, the findings underscore the need to expand digital support, promote community-based services, and enhance caregiver training and intergenerational activities to create inclusive, dementia-friendly ecosystems in Greece.

Current status of dementia in Greece

Greece currently faces a growing dementia challenge, with approximately 200,000 people living with dementia, most frequently Alzheimer's disease, and 400,000 informal caregivers, mainly family members, supporting them[1]. More specifically, about 5% of people over 65 in Greece have dementia, and the rate gets higher as people get older (Tsolaki et al., 2021). While rates remain stable, projections reveal a stipper increase toward 2050, putting more pressure on the healthcare and social support systems[2].

In addition the above, strong support from the public and NGOs led Greece to launch its first National Dementia Strategy in 2014. It was made official by a law and through the creation of the National Observatory for Dementia and Alzheimer's Disease later that year[3]. The National Action Plan (2016–2020) targets: Dementia registry & monitoring, Public and professional awareness, Support for caregivers, Early diagnosis and treatment pathways, Dementia-friendly legislation, Research and training, Education campaign. To execute these initiatives, Greece has built: Memory Clinics in universities and hospitals (21 nationwide), Day Care Centers (21 existing, plus 18 municipal centers), Home care services for immobile patients, Hospice units under development[4].

The Athens Alzheimer Association (AAA) leads dementia care in Greece through the offer of free services like memory clinics, day care centers, home care, and support for caregivers. Moreover, it trains staff, raises awareness, and supports research. AAA helped develop the National Action Plan and set up local counseling centers in over 50 municipalities. Dementia costs Greece about 3 billion euros each year (Sexton et al., 2024). Although services are growing, the country still needs a national registry and better funding. New tools like the R4Alz test and smart technologies are starting to improve care (Sexton et al., 2024).

Greece faces several challenges in dementia care. Services are unevenly distributed, with rural areas lacking support. Additionally, limited funding decreases the growth of registries, day care centers, and hospices. Most care depends on family members, as 89% of patients stay at home. Stigma and low public awareness also remain major barriers, highlighting the need for targeted education campaigns.

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[1] Greek National Observatory for Dementia – Alzheimer (Source: https://www.moh.gov.gr/articles/ethniko-parathrhthrio-gia-thn-anoia-alzheimer/greek-national-observatory-for-dementia-alzheimer/)
[2] Dementia in Greece (Source: https://www.p-consulting.gr/en/dementia-in-greece/)
[3] Greek National Observatory for Dementia – Alzheimer (Source: https://www.moh.gov.gr/articles/ethniko-parathrhthrio-gia-thn-anoia-alzheimer/greek-national-observatory-for-dementia-alzheimer/)
[4] Alzheimer Athens (Source: https://alzheimerathens.gr/en/#:~:text=Alzheimer%20Athens%20is%20a%20non,with%20dementia%20and%20their%20families)

Best practices in Greece

Evidence from Desk Research

Greece has implemented a range of best practices combining traditional care, community outreach, and emerging digital tools:

1. **Community-based, integrated care**

Athens Alzheimer Association (AAA) and Alzheimer Hellas run free memory clinics, day-centers, home-care services, caregiver support, and public awareness programs across urban and regional centers[5]. Furthermore, the NGO "Frodizo" in Patras runs a program called "Dementia intervention at home." It offers weekly home visits with mental exercises, physical activities, and support for caregivers. This enables reduce stress for families[6].

2. **Tele-support & helpline services**

The Greek Dementia Helpline (1102), launched in 2021, offers free telephone, email, and chat counseling by psychologists, neurologists, and social workers. By October 2021, it had reached 8,000 callers and boosted caregiver confidence and service navigation (Blekou et al., 2022).

3. **Digitally interconnected rural mental health care**

INTRINSIC, a network led by Patras and Athens universities, connects rural primary care and tertiary psychiatry via a digital platform. It supports screening, treatment coordination, and surveillance in remote areas (Alexopoulos et al., 2023).

4. **Digital literacy & tech workshops for people with dementia**

In Larissa, the Alzheimer Larissa group has promoted digital literacy since 2021, teaching tablet use and even organizing creative 3D-pen sessions to boost confidence and creativity[7].

5. **Culturally adapted e-learning for caregivers**

AAA adapted and piloted the WHO iSupport platform (April 2020–March 2021). Over 160 Greek caregivers have completed online training modules to improve care knowledge and reduce burden (Efthymiou et al., 2022).

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[5] Alzheimer Athens (Source: https://alzheimerathens.gr/en/#:~:text=Alzheimer%20Athens%20is%20a%20non,with%20dementia%20and%20their%20families)

[6] GSGs OBSERVATORY (Source: https://observatory.sustainable-greece.com/en/practice/program-quotdementia-intervention-homequot.1295.html)

[7] Alzheimer Europe (Source: https://www.alzheimer-europe.org/news/alzheimer-larissa-greece-supports-digital-literacy-people-dementia-creative-session-using-3d?language_content_entity=en)

6. Emerging AI/AR-enhanced mental health training

The Pytheia digital mental health center in Larisa explores AI and augmented reality for training healthcare workers and seniors, promising personalized simulations, diagnostics, and self-management tools[8].

Evidence from Field Research

Insights from Social Services

1. **Personalized and person-centered care:** Staff adapt daily to the needs of each individual, employing different therapeutic techniques depending on the day. This includes cognitive stimulation, music therapy, singing, and arts and crafts. A strong human-centered approach—focused on listening to and responding to each person's unique needs—was seen as critical for success.
2. **Cognitive empowerment and intergenerational activities**: Programs often include activities that bring together older adults and younger generations (e.g., family members), fostering social connection and emotional well-being.
3. **Creative and therapeutic models**: Some services use drama therapy and dynamic care models to engage clients in meaningful, expressive activities.
4. **Digital tools in practice**: Social services reported the use of tablets and smart TVs during group activities for digital cognitive stimulation. Other centers employ fall detection sensors (sometimes connected to cameras), electronic nurse call bells, and even AI tools to explore new techniques for cognitive enhancement.

Feedback from Family Caregivers

1. **Importance of routine**: Several respondents emphasized that the establishment of a daily schedule enabled their relatives stay alert during the day and sleep better at night. Structured days with predictable activities reduced stress and confusion.
2. **Inclusion in everyday life**: Family caregivers make efforts to involve individuals with dementia in regular household tasks, helping them maintain a sense of connection and purpose.
3. **Social engagement**: Going for walks or visiting cafés and parks with family or friends helps improve mood, behavior, and prevents people from feeling alone.
4. **Self-help and peer support**: Some caregivers reported that participation in peer support groups offered emotional relief and practical strategies. Others highlighted the positive impact of professional in-home nursing care when balancing work and caregiving responsibilities.

[8] Revolutionizing Mental Health Care in Greece (Source: https://pytheia.gr/en/digital_mental_health/)

5. **Challenges and gaps**: Several caregivers expressed feelings of exhaustion, uncertainty, and emotional burden, especially when facing advanced symptoms with limited support.

Feedback from Professional Caregivers

1. **Individual cognitive stimulation sessions**: These are widely used and perceived as one of the most beneficial interventions for maintaining engagement and reducing boredom.
2. **Intergenerational programming**: When family members or children join activities at the care center, it lifts people's spirits and helps them feel more connected to life outside.
3. **Use of digital cognitive tools**: Platforms offering digital brain games or memory exercises are increasingly used, particularly with younger clients or those in early stages of dementia. These tools seem to foster motivation and enjoyment.
4. **Creative group activities:** Day care centers often organize group singing, ceramics, and crafting sessions, which are well-received and support both social and emotional wellbeing.

The field data strongly supports the integration of personalized, routine-based, and socially engaging interventions, that are enhanced by selective digital tools such as tablets, cognitive apps, and fall sensors. These practices appear to improve quality of life, reduce caregiver burden, and foster meaningful connections across families and care environments. Continued development of intergenerational programming, digital cognitive platforms, and community engagement strategies is essential for the successful building of dementia-inclusive ecosystems in Greece.

Conclusions and recommendations

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Greece has made important progress in dementia care, since it combines personalized support, community-based programs, and emerging digital tools. Best practices highlight the value of daily routines, social and intergenerational activities, and the use of digital platforms for cognitive support.

However, the reliance on family caregivers, unequal access across urban and rural areas, and limited funding remain pressing issues. The emotional and practical toll on caregivers, especially in later stages of dementia, calls for stronger support frameworks.

Recommendations:

1. **Expand Digital Infrastructure**: Scale up access to digital platforms (e.g., cognitive apps, teleconsultations, fall detection systems) especially in rural and underserved areas.
2. **Invest in Caregiver Education**: Broaden access to culturally adapted digital training programs like iSupport and introduce structured peer support networks.
3. **Strengthening Community Integration**: Support intergenerational and socially engaging programs that foster community ties and reduce isolation.
4. **Standardize Services Nationwide**: Develop a national registry and monitoring system to track dementia prevalence and service usage, guiding equitable resource distribution.
5. **Promote Public Awareness**: Continue educational campaigns to reduce stigma and improve early diagnosis and help-seeking behavior.

Continued cross-sector collaboration, including government, NGOs, families, and tech innovators, will be essential to build a sustainable, inclusive, and digitally enabled dementia care framework in Greece.

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Links

Greek National Observatory for Dementia – Alzheimer
(Source: https://www.moh.gov.gr/articles/ethniko-parathrhthrio-gia-thn-anoia-alzheimer/greek-national-observatory-for-dementia-alzheimer/)
Dementia in Greece (Source: https://www.p-consulting.gr/en/dementia-in-greece/)

Alzheimer Athens (Source: https://alzheimerathens.gr/en/#:~:text=Alzheimer%20Athens%20is%20a%20non,with%20dementia%20and%20their%20families)
GSGs OBSERVATORY (Source: https://observatory.sustainable-greece.com/en/practice/program-quotdementia-intervention-homequot.1295.html)
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Revolutionizing Mental Health Care in Greece
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