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STRATEGY FOR DEMENTIA MANAGEMENT IN SLOVENIA UNTIL 2030

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ABBREVIATIONS USED

NIJZ – National Institute of Public Health
ReNPDZ18–28 – Resolution on the National Mental Health Programme 2018–2028
ReNPSV22–30 – Resolution on the National Social Assistance Programme 2022–2030
ReNPZV16–25 – Resolution on the National Healthcare Plan 2016–2025: Together for a Healthy Society
WHO – World Health Organization
UMC – University Medical Centre

1 INTRODUCTION

The number of older people in the world is increasing. Healthy ageing policies direct attention towards strengthening the active abilities of individuals, which also enables older people to live a full and creative life. Measures to ensure healthy ageing must be carried out at several levels, and activities to ensure health promotion, disease prevention, the maintenance of physical and mental capabilities and development of creative abilities of people throughout their lives must be performed in several areas. The government and society can have a considerable influence on many factors contributing to active and healthy ageing. However, the key to this is awareness and the responsible care of every individual[1] for a healthy lifestyle.

Slovenia is a country with a long-lived society. Life expectancy is increasing and the share of the population older than 65 years is growing, currently amounting to 20.9%. Considering the trend in life expectancy, the changes in Slovenia's population structure will become even more pronounced. By 2030, the share of the population aged 65 and more will increase to 24.8%, and by 2060 to 29.5%. Demographic changes reflect the development of modern society and are a fact to which we must adapt our current systems and arrangements, in order to create conditions for the quality of life and ageing with dignity of all generations. Ageing increases the disease burden and the need for long-term care.

Dementia is one of the greatest challenges of a long-lived society. The term dementia means a progressing and emerging condition indicated by impairments of memory, cognition, orientation, recognition, understanding, speech, judgment, behaviour, sensation and feeling. This limits the affected person's day-to-day activities and leads to their needing the assistance of others. The estimated economic burden of dementia in Slovenia in the period 2015–2017, calculated according to the cross-sectional method, was around EUR 11.4 million per year or 0.3% of all healthcare expenditure. The World Health Organization (hereinafter: WHO) calculated the global dementia costs in 2015 at 818 billion USD or 1% of global GDP.[2]

Dementia is caused by neurodegenerative, vascular, inflammatory or other brain diseases, which a person develops gradually. With modern neurological diagnostic approaches using biomarker analysis and neurophysiological and advanced imaging methods, the nature of the disease’s process can be determined in its early stages when the clinical picture of dementia has not yet developed. An early accurate diagnosis ensures the selection of the appropriate therapeutic approach, the prognosis of the disease and the design of post-diagnosis treatment. It also makes dealing with the disease easier for the person with dementia and their family and allows them to plan for the future.

There are many risk factors for the development of dementia, which to a great extent depend on the person's environment, lifestyle and certain underlying health conditions, the effective treatment of which can prevent the development of dementia. The greatest fixed risk factor is age, although some people get dementia even before the age of 65 (9% of dementia patients are in that category). Dementia presents a great challenge and cost[3] for society. It is the main cause of dependence on others and disability among older Europeans.[4] According to the Global action plan on the public health response to dementia 2017–2025 (WHO, 2017[5]; hereinafter: WHO Global Action Plan) and the Intersectoral global

[1] This text uses the masculine grammatical form in the Slovenian original to refer to all genders, including references to occupations.
[2] Lovrečič, B., and Lovrečič, M. (ur). Spremljanje demence v Sloveniji, Epidemiološki in drugi vidiki, ZRC SAZU, 2021, https://doi.org/10.3986/9789610505785, https://omp.zrc-sazu.si/zalozba/catalog/view/1970/8123/1513-2, DOI: 10.3986/9789610505785.
[3] Prince, M., Wimo, A., Guerchet, M., Ali, G. C., Wu, Y.-T., and Prina M. World Alzheimer Report 2015. The global impact of dementia: an analysis of prevalence, incidence, cost and trends. Alzheimer’s Disease International, 2015.
[4] WHO. Noncommunicable diseases, https://www.who.int/health-topics/noncommunicable-diseases#tab=tab_1
[5] WHO. Global action plan on the public health response to dementia 2017–2025, WHO 2017, https://apps.who.int/iris/rest/bitstreams/1092215/retrieve

action plan on epilepsy and other neurological disorders (WHO, 2021[6]), governments should treat dementia as a public health priority, raise public awareness and reduce dementia risks, set up appropriate treatment, care and support mechanisms for people with dementia and support mechanisms for their carers, and promote a research environment, innovations and innovative approaches.

The Glasgow Declaration[7] calls for the creation of a European dementia strategy and national strategies in every country in Europe. We are called on to ensure the rights, dignity and autonomy of people with dementia and to mitigate the negative impact of dementia on society. There is still a strong stigma attached to dementia, which affects the time of diagnosis, the life of patients and their families and the financial cost for society. The main recommendation of the Alzheimer Europe and Alzheimer's Disease International organisations is to raise awareness, which will contribute to timely treatment and access to services. By reducing the risk factors that we can control, we will contribute to dementia developing later in people's lives and thus reduce the societal financial burden. Due to the nature of the disease, a legal framework must also be set up for treating people with dementia as people with a disability.

In 2016, Slovenia adopted the Strategy for dementia management in Slovenia until 2020. The second Strategy for dementia management in Slovenia until 2030 (hereinafter: Strategy) provides for the continuation and upgrade of the planned and coordinated activities for managing dementia set out in the first strategy. The goals achieved under the previous strategy include awareness-raising, stigma reduction and the training of carers and healthcare, social assistance and long-term care professionals. In 2017 and 2018, the Ministry of Health co-financed nine training and awareness-raising programmes for dementia management. Under two of these programmes training for healthcare professionals was provided, while under the remaining seven training courses for formal and informal carers of people with dementia were carried out in all Slovenia's regions. More than 13,000 attendees directly participated in the training programmes, while more than half of Slovenia's population participated indirectly based on the published materials and publications in the media. Under one of the programmes, the association Spominčica set up a network of Dementia-Friendly Points, through which it continues to raise awareness and increase the accessibility of services for people with dementia in local environments. In addition to the competent and engaged project implementers, the success of the programmes was also greatly due to the excellent cooperation between the Ministry of Health and the Ministry of Labour, Family, Social Affairs and Equal Opportunities, which should be used as an example and guideline for pursuing the goals of this Strategy. The cooperation between the two ministries proved to be an effective approach and should continue also with regard to this Strategy. The goals that have not been achieved include the introduction of epidemiological studies and the setting-up of a national register and a network of memory centres, and adapted assistance for people with dementia in home care (the majority of people with dementia live at home). This Strategy gives more attention to care in the community, the regulation of the status of people with dementia, and support for the families. It is supplemented by the Long-Term Care Act (Official Gazette of the Republic of Slovenia [*Uradni list RS*], Nos 196/21, 163/22 and 18/23 – ZDU-1O). The aim of the Strategy is to implement the Glasgow Declaration and the WHO Global Action Plan 2017–2025.

Detailed tasks to achieve particular goals, and financing sources and implementation indicators for the Strategy, will be determined in action plans, which will determine the monitoring of the Strategy's implementation.

The Minister of Health will appoint a Council for Dementia Management to monitor the implementation of the Strategy. In order to monitor the fulfilment of goals and tasks set out by the action plans, the Ministry of Health will prepare annual reports on the implementation of the Strategy, which will then be considered and adopted by the Council for Dementia Management. The Ministry of Health also

[6] WHO. Intersectoral global action plan on epilepsy and other neurological disorders 2022–2031, WHO, 2021, https://cdn.who.int/media/docs/default-source/mental-health/english_discussion-paper_epilepsy-and-other-neurological-disorders_050321.pdf?sfvrsn=eec245a2_96&download=true

[7] The Glasgow Declaration 2014 was adopted on 20 October 2014 by delegates from 26 members of Alzheimer Europe.

determines the method of monitoring the Strategy's implementation and the responsible persons of the participating stakeholders.

1.1 Aim, goals and principles of the Strategy

This Strategy is the basic document and allows for a coordinated and comprehensive approach of all stakeholders to dealing with dementia and similar conditions. The aims of the Strategy are to ensure preventive measures (educating and encouraging the population to live in a healthy way, eat a balanced diet and engage in regular physical and mental activities), early detection of the disease, appropriate integrated post-diagnosis treatment of people with dementia (while respecting fundamental human rights in accordance with the Glasgow Declaration), support for families and informal carers, destigmatisation of the disease, development of a dementia-friendly environment and promotion of research. The Strategy sets out measures that will ensure public access to information on dementia, provide, as far as possible, for the needs of people with dementia and their families and ensure sufficient support in all environments. Special attention is given to vulnerable groups.

Another aim of the Strategy is to improve Slovenian data on dementia and set up a national register, which is in accordance with the WHO Global Action Plan's target of 50% of countries routinely collecting a core set of dementia indicators for epidemiological surveillance of dementia through their national health and social assistance and long-term care information systems by 2025.

The goals of the Strategy are:

1. **to promote prevention programmes for reducing risk factors and for maintaining and improving health in the community using various approaches aimed at particular groups and individuals:**
   - strengthening protective factors and reducing risk factors for dementia,
   - identifying risk factors in the population, introducing activities for preventing fragility, identifying cognitive impairment early and preventing cognitive decline, actively participating in prevention programmes at the local level and creating dementia-friendly environments,
   - raising awareness in the general and target populations of healthy living and the prevention of dementia risk factors,
   - introducing uniform screening tests in accordance with expert recommendations;

Indicator	Baseline value/estimate	Target value/estimate
Share of national healthcare and social assistance programmes providing measures that, in part or in full, expressly apply to people with dementia	5% <	15% >

2. **to diagnose early stages of neurocognitive impairments, and improve access to quality, safe and effective healthcare treatment and medical treatment:**
   - ensuring early and timely diagnostics and start of medical treatment,
   - providing and formalising non-pharmacological approaches in treating people with dementia,
   - providing integrated services and interdisciplinary treatment from the start,
   - improving the accessibility and quality of healthcare services for early diagnosis of an impairment presented as dementia,
   - improving and standardising diagnostic procedures, adopting a polycentric approach at the national level by setting up a network of memory centres, and setting staff norms for

interdisciplinary team treatment to provide medical treatment and care to people with dementia in accordance with modern clinical trends,
- expanding the existing treatment at the tertiary healthcare level in case of complex clinical pictures with access to modern diagnostic and treatment methods,
- ensuring quality, accessible and effective treatment by introducing quality indicators;

Indicator	Baseline value/estimate	Target value/estimate
Number of people with dementia receiving timely and appropriate treatment	20% <	50% >

3. **to improve access to appropriate and coordinated post-diagnosis interdisciplinary treatment for people with dementia, including integrated treatment, long-term care, social services, support for families or carers in the local environment and access to palliative treatment:**
   - ensuring the quality, effective and comprehensive treatment of people with dementia adapted to the type and stage of dementia,
   - improving the effectiveness of service provision and human and financial resource management,
   - empowering people with dementia and their families to maintain their independence,
   - improving the quality of life of people with dementia and their families,
   - adapting the provision of services to the needs and abilities of the person with dementia who needs these services,
   - ensuring the accessibility of long-term care and social assistance and healthcare services to support people with dementia, their families and carers, and increasing community-based services,
   - expanding the network of services and programmes in long-term care, social assistance and healthcare services, and improving the choice of service options,
   - organising and providing services in a way that is adapted to the person with dementia and is friendly to and respectful of them,
   - defining the criteria and method of palliative treatment for people with dementia;

Indicator	Baseline value/estimate	Target value/estimate
Number of people with dementia receiving integrated community-based treatment	10% <	40% >
Reduction of the number of people with dementia waiting for admission to a social care institution for more than 6 months	30% >	10% <
Definition of the criteria and method for the palliative treatment of people with dementia within a national palliative care programme	0%	100%

4. **to use modern information and communication technologies (hereinafter: ICT) in treating and supporting people with dementia:**
   - developing support using ICT to ensure as independent a life as possible in the home environment, in accordance with the Long-Term Care Act,

- ensuring the flow of data on detected cognitive decline, performed diagnostic procedures, treatment and post-diagnosis treatment between the healthcare, social assistance and long-term care systems,
- setting up an information and consultation system to support people with dementia and their families or carers;

Indicator	Baseline value/estimate	Target value/estimate
Establishment of support for people with dementia and their families using ICT	3% <	30% >

5. **to increase respect for the dignity of people with dementia, reduce stigma and raise awareness in the general public and the professional community in order to establish dementia-friendly communities:**
   - destigmatising dementia,
   - recognising and advising and acting on the signs of abuse, violence and neglect,
   - empowering people with dementia,
   - providing legal support regarding the protection of rights of people with dementia;

Indicator	Baseline value/estimate	Target value/estimate
Share of people with dementia and their family members included in empowerment programmes	30% <	80%

6. **to educate all occupational groups in dementia management:**
   - provide appropriate knowledge and skills to all staff coming into contact with people with dementia,
   - provide upskilling and training for the employees of healthcare, long-term care and social assistance providers;

Indicator	Baseline value/estimate	Target value/estimate
Share of employees included in additional upskilling and training in communication and work with people with dementia	30% >	80% >

7. **to set up a database on dementia at the national level:**
   - setting up a national register for monitoring the incidence, prevalence and clinical and other characteristics of dementia,
   - recording the common and rare forms of dementia and characteristics related to the care and medicinal products and non-pharmacological treatment,
   - presenting sociodemographic characteristics of people with dementia, and the status and quality of care of people with dementia in Slovenia;

Indicator	Baseline value/estimate	Target value/estimate
Data set for monitoring the incidence, prevalence and treatment of people with dementia	30% <	90% >

8. **to promote modern research on dementia:**
   - formulating a proposal for priority research directions at the national level,
   - ensuring the diversity and balance of research categories with regard to dementia,

- ensuring the coordination of research, improving the overview of research work and proposing/introducing national and/or international criteria for assessing the quality of studies,
- setting up a system for epidemiological studies on people with dementia,
- promoting interdisciplinary and polycentric cooperation among researchers at the national and international levels;

Indicator	Baseline value/estimate	Target value/estimate
Definition of national priority research directions for at least 5 years	10% <	100%
Research on dementia in accordance with national priorities	40% <	90% >
Increase in the number of studies at the national and international levels	40% <	70%

9. to establish a national dementia centre to:
- monitor developments in medicine regarding dementia at the national and international levels,
- ensure the effective, quality and efficient implementation of the Strategy,
- coordinate and direct the development of activities related to prevention and other services for dementia management,
- provide support to professionals in treating people with dementia,
- monitor and provide training, education and research at the international and national levels,
- plan and set up a network of memory centres;

Indicator	Baseline value/estimate	Target value/estimate
National centre for cognitive decline	10% <	90% >
Establishment of a network of regional memory centres in health regions	10% >	70% >

10. to adequately treat people with dementia during epidemics and other emergency situations:
- preparing guidelines for the protection and treatment of people with dementia during epidemics and other emergency situations,
- promoting and organising digital and other technologically adapted support for people with dementia and carers during emergency situations,

Indicator	Baseline value/estimate	Target value/estimate
Guidelines for the protection and treatment of people with dementia during epidemics and other emergency situations	20% >	100%

With regard to measures for achieving its goals, the Strategy takes into account the principles of:

1. an interdisciplinary approach and integrated treatment,
2. destigmatisation in the professional community and the general public,
3. objectivity in planning measures based on real possibilities,
4. individual treatment approach,
5. equal access to services,
6. respect for human rights and dignity,

7. financial sustainability.

2 BASIS FOR THE STRATEGY

Dementia is a public health priority, globally and in Slovenia. People younger than 65 years can also get dementia, and they represent 9% of dementia patients.[8] Due to population ageing, the number of people with dementia is rapidly increasing (the increase is particularly fast in the age group over 80)[9]. Demographic changes reflect the development of modern society and are a fact to which we must adapt our current systems and arrangements, in order to create conditions for the quality of life and ageing with dignity of all generations. Ageing increases the disease burden and the need for long-term care. Slovenia adopted the Long-Term Care Act, which regulates this area at the systemic level.

Figure 1: Population pyramid of Slovenia, 1 July 2021 Source: Statistical Office of the Republic of Slovenia

Figure 2: Projection for the population pyramid of Slovenia in 2051 Source: Statistical Office of the Republic of Slovenia

In addition to demographic trends, data on one-person households are also important. In 2021, every seventh resident of Slovenia lived alone.[10] The data on the increase in the number of one-person households in the age group over 65 years, in particular among women, are very relevant for the preparation of special measures and goals to provide adequate support with regard to both prevention activities and post-diagnosis treatment for people with dementia who live alone.

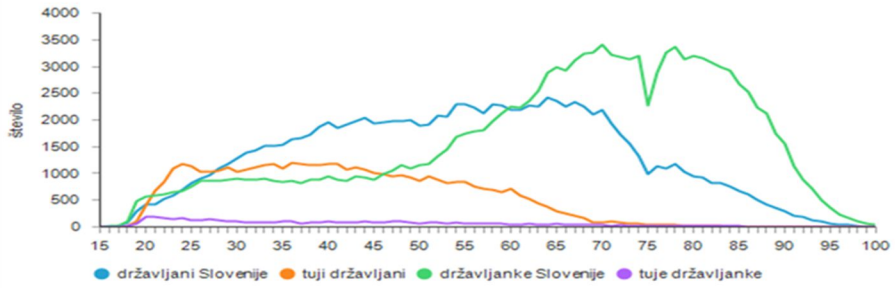

Figure 3: One-person households in Slovenia[11]

Data on the incidence and prevalence of dementia are inadequate. Statistical data show that 22,711 women and 9,324 men aged between 30 and 95 years have been diagnosed with dementia.[12] It is

[8] Loy, C. T., Schofield, P. R., Turner, A. M., and Kwok, J. B. J. Genetics of dementia. Lancet. 2014; 383(9919): 828–840, doi:http://dx.doi.org/10.1016/ S0140-6736(13)60630-3.

[9] On 1 January 2021, the population of Slovenia was 2,108,977, 20.19% of which was older than 65 years and 5.44% older than 80 years. It is estimated that by 2030 Slovenia's population will be 2,079,967, 25% of which will be over 65 years old and 6.8% over 80 years old. The age structure of Slovenia's population will change significantly in the next decades.

[10] There were 292,301 one-person households, which was every third household (34%). In the age group up to 63 years, the majority of people living alone were men, while in the age group 64 years and over the majority were women. The average age of women living alone was 64.7 years. On average, they were 13.4 years older than men living alone. Statistical Office of the Republic Slovenia, https://www.stat.si/StatWeb/News/Index/9973

[11] Statistical Office of the Republic Slovenia, https://www.stat.si/StatWeb/News/Index/9973

[12] eDemenca. STANJE GLEDE DEMENCE PO SVETU IN V SLOVENIJI? https://edemenca.si/kaksno-je-stanje-glede-demence-po-svetu-in-v-sloveniji

estimated that in 2019, there were approximately 43,038 people with dementia in Slovenia.[13] The number is expected to double by 2035 due to demographic trends. Each patient is cared for by three people, which means that approximately 150,000 relatives, friends and other people taking care of people with dementia are indirectly affected.[14]

Effective medical treatment of underlying health conditions prevents the development of dementia. There are also known risk factors, which depend on the person's environment, lifestyle and certain underlying health conditions. Protective factors for dementia include taking care of one's physical health and fitness by engaging in physical and mental activities, good adaptation to changes and stressful situations, active social life and participation in activities that are important to older people and which they look forward to (leisure activities, voluntary work, education, taking care of grandchildren, etc.).

In Slovenia, there are considerable differences among regions with regard to the accessibility of healthcare services for people with dementia. There is a severe shortage of staff at the primary healthcare level, the number of family doctors, clinical psychologists, psychiatrists and neurologists is insufficient to meet the needs of the population, gerontology is still in development and there is still no adequate integrated community-based treatment. Early diagnosis ensures that the person with dementia and their family have an appropriate approach and a proper way of dealing with the disease, and allows them to plan for the future.

Stigma is a factor that hinders dementia management and reduces the quality of life of people with dementia. There is still a strong stigma attached to dementia in society, which affects the time of diagnosis, the life of patients and their families and the financial cost for society. Several international documents bind us to ensure the rights, dignity and autonomy of people with dementia.

In order to develop a dementia-friendly environment, we must improve cross-sectoral cooperation and include people with dementia, their families, non-governmental organisations (hereinafter: NGOs) and other stakeholders in the local environment in measure planning and implementation.

The local environment has a great impact on ensuring the quality of life of people with dementia, in particular by promoting a diverse set of services for them and providing various forms of assistance and programmes that help carers in taking care of people with dementia. The forms of assistance and programmes also greatly affect the development of a dementia-friendly environment, which they ensure by raising public awareness and providing training for employees in public and other services who most often come into contact with people with dementia.

People with dementia may perceive their surroundings as chaotic, unpredictable, full of obstacles and even dangerous. A well-arranged and adapted environment helps them maintain their abilities, strengthens their independence and encourages them to be active and participate. A dementia-friendly environment:

- non-intrusively reduces risks,
- respects and creates a humane criterion,
- allows people with dementia to be "seen and heard",
- reduces unnecessary stimulation,
- optimises beneficial stimulation,
- allows and supports movement, inclusion and engagement,
- creates a known space that expresses people's life stories,
- provides opportunities for socialising but respects people's need to be alone,

[13] Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019, Lancet Public Health 2022, https://doi.org/10.1016/S2468-2667(21)00249-8. Based on the data and projections for 2050, it is estimated that there are currently 43,038 (36,793–50,186) people with dementia in Slovenia, and that in 2050 there will be 84,735 (69,330–101,544).

[14] eDemenca. STANJE GLEDE DEMENCE PO SVETU IN V SLOVENIJI? https://edemenca.si/kaksno-je-stanje-glede-demence-po-svetu-in-v-sloveniji

- creates paths and connections to local communities,
- follows, respects and enables people's own vision of the way of life.

Such an environment must be provided at both micro and macro levels, from cities, towns, streets and own or sheltered housing to the renovation or building of new construction projects, care homes, hospitals and day centres.[15]

In accordance with the WHO recommendations, the Strategy sets out measures in the following areas:
- dementia as a public health priority,
- public awareness of dementia and dementia-friendly environments,
- reduction of dementia risk factors,
- access to early diagnosis and post-diagnosis treatment,
- support for and education of families and other informal carers of people with dementia
- dementia information system,
- research and innovative approaches.

In order to achieve the goals in the aforementioned areas, the Strategy sets out many measures which supplement other national strategies (in particular, those in healthcare, long-term care and social assistance), and defines the entities responsible, indicators, financial resources and time limits. The Strategy sets out the establishment of entities responsible for managing, coordinating and evaluating the implementation of goals that will affect the development of dementia management in Slovenia.

2.1 Awareness and destigmatisation of the disease

By reducing the risk factors that we can control, we will contribute to the disease developing later in people's lives and thus reduce the societal financial burden. Raising public awareness of risk factors, the first symptoms of dementia, the importance of early diagnosis and an appropriate approach to people with dementia and their relatives are public health priorities. Although the greatest risk factor is old age, raising awareness can reduce other known dementia risk factors, which mostly depend on the person's environment, lifestyle and certain underlying health conditions, the treatment of which can reduce the risk of dementia.

Structural stigmatisation is shown by denial of the problem, inadequate care and even neglect of and disrespect for people with dementia. The individual with their abilities and dignity must be put first, not the disease. Stigma leads to people seeking help late and to a prevailing feeling of inferiority, which significantly contributes to poor treatment outcomes and loss of hope. According to WHO, stigma is the main obstacle to establishing appropriate, quality and accessible mental health services. Therefore, special measures are designed to reduce the stigma.

2.2 Legal basis and important documents

In accordance with the Health Care and Health Insurance Act[16], Slovenia provides for the care of people with dementia, the financing of healthcare services, healthcare staff, including their training and upskilling, nursing and rehabilitation in institutional care and home care. The system ensures the provision of healthcare services. The Long-Term Care Act establishes a system of rights to long-term care services. Currently, it is in the process of coordination with other healthcare, long-term care and social assistance areas. In addition, prevention programmes are being planned and developed to reduce

[15] The good care Group, Recognising The Role Of The Specialist Dementia Nurse In The Community, https://www.thegoodcaregroup.com/news/recognising-role-specialist-dementia-nurse-community/

[16] Health Care and Health Insurance Act (Official Gazette of the Republic of Slovenia [*Uradni list RS*], Nos 72/06 – official consolidated version, 114/06 – ZUTPG, 91/07, 76/08, 62/10 – ZUPJS, 87/11, 40/12 – ZUJF, 21/13 – ZUTD-A, 91/13, 99/13 – ZUPJS-C, 99/13 – ZSVarPre-C, 111/13 – ZMEPIZ-1, 95/14 – ZUJF-C, 47/15 – ZZSDT, 61/17 – ZUPŠ, 64/17 – ZZDej-K, 36/19, 189/20 – ZFRO, 51/21, 159/21, 196/21 – ZDOsk, 15/22, 43/22, 100/22 – ZNUZSZS, 141/22 – ZNUNBZ and 40/23 – ZČmIS-1).

the needs for long-term care, including services for strengthening and maintaining independence, and conditions and opportunities are being created for equal access to long-term care services in Slovenia and for the effective and efficient organisation of such care. National programmes play an important role in improving the provider network, developing the field and keeping up with advances in the field, in particular the Resolution on the National Mental Health Programme 2018-2028 (ReNPDZ18–28)[17], the Resolution on the National Healthcare Plan 2016–2025: Together for a Healthy Society (ReNPZV16–25)[18] and the Resolution on the National Social Assistance Programme 2022–2030 (ReNPSV22–30)[19].

The Healthcare Databases Act[20] does not systemically regulate national registers, which is a deficiency in regulation that must be rectified in order to set up a national dementia register. The legal basis for restricting the rights of people with dementia and for possibilities or conditions for their empowerment must be re-examined and amended, as necessary, while ensuring that this does not put the physical and economic security of people with dementia at risk. Considering the above, the Strategy gives special attention to preventing the neglect and abuse of people with dementia.

2.3 Other important acts and documents

The Convention on the Rights of Persons with Disabilities[21] requires signatory states to, among other things, support deinstitutionalisation and enable people with disabilities to live at home as long as possible.

The WHO Global Dementia Observatory is a control mechanism for monitoring the seven priority areas under the WHO Global Action Plan and data exchange among Member States.

The basis for formulating a European dementia strategy and national strategies in every European country is the Glasgow Declaration, which calls for ensuring the rights, dignity and autonomy of people with dementia and mitigating the negative impact of dementia on society.

2.4 Programmes and services for people with dementia and their families

There is an alarming shortage of staff in healthcare and social assistance in Slovenia. The greatest challenge for the providers of healthcare and social assistance services for managing dementia is the shortage of qualified staff and a lack of cohesion among services and sectors. Staff shortage is particularly acute in the primary healthcare network. The number of family doctors, clinical psychologists, occupational therapists, physiotherapists, psychiatrists, neurologists, nurses and other healthcare professionals is insufficient to cover the needs of the population. Furthermore, there are no geriatricians and the knowledge in gerontology is inadequate. Healthcare is presented in detail in Chapter 3.

The network of social assistance services and programmes is determined by the national social assistance programme, which pursues the following goals: to ensure the accessibility and availability of services and programmes, and to improve the ratio between the institutional and community-based care in favour of community. Although the ratio between these two types of care services is improving,

[17] Resolution on the National Mental Health Programme 2018−2028 (Official Gazette of the Republic of Slovenia [*Uradni list RS*], No 24/18).
[18] Resolution on the National Healthcare Plan 2016–2025: Together for a Healthy Society (Official Gazette of the Republic of Slovenia [*Uradni list RS*], No 25/16).
[19] Resolution on the National Social Assistance Programme 2022–2030 (Official Gazette of the Republic of Slovenia [*Uradni list RS*], No 49/22).
[20] Healthcare Databases Act (Official Gazette of the Republic of Slovenia [*Uradni list RS*], Nos 65/00, 47/15, 31/18, 152/20 – ZZUOOP, 175/20 – ZIUOPDVE, 203/20 – ZIUPOPDVE, 112/21 – ZNUPZ, 196/21 – ZDOsk, 206/21 – ZDUPŠOP, 141/22 – ZNUNBZ and 18/23 – ZDU-1O).
[21] Act Ratifying the Convention on the Rights of Persons with Disabilities and the Optional Protocol to the Convention on the Rights of Persons with Disabilities (Official Gazette of the Republic of Slovenia – International Agreements [*Uradni list RS – Mednarodne pogodbe*], No 10/08).

institutional care is still prevalent. Notable progress has been made in adapting institutional care services to the needs of people with dementia, including by creating friendlier living environments, but the expansion and adaptation of community-based services are not yet aligned with the needs. For this reason, the goals of the Resolution on the National Social Assistance Programme (ReNPSV22–30) include the expansion of community-based services and adaptation of services to people with dementia, in particular services such as home help, day care and short-term stay.

The employees of service providers receive training in working with people with dementia. Training and upskilling are essential for further development and adaptation of services and must be planned and targeted.

A decline in dementia stereotypes has been detected in recent years. This is also due to the increase in activities under social assistance programmes aimed at raising awareness and educating people with dementia, their families and people in their environment. Social assistance programmes adapted to work with people with dementia provide various forms of assistance and must be strengthened in the future.

Despite the many activities of the providers of social assistance services and programmes, it has been noted that people with dementia and their families or informal carers are still insufficiently informed of the available services and programmes and options for inclusion, which must be rectified in the future.

There are many programmes and services available in Slovenia for people with dementia and their families. They are provided at the local and national levels, by public services, NGOs and other providers. It has been noted that there are considerable differences among regions in the accessibility of services within the public healthcare network, and there is no adequate overview of the many programmes and services provided by NGOs. It can reasonably be assumed that services and programmes for people with dementia and their families are not so effective as they could be if they were planned appropriately at the national level and in cooperation with local communities. The above-mentioned deficiencies will be corrected when a national centre for dementia management at the tertiary healthcare level is set up.

2.5 Protection of the rights of people with dementia and their families

2.5.1 Glasgow Declaration (rights of people with dementia and their families)

Dementia is a disease which is still heavily stigmatised in society. The main recommendations of the Alzheimer Europe and Alzheimer's Disease International organisations to all members is to increase the activities for raising awareness of dementia in the general public and professional community, improve the recognition of early symptoms of the disease and reduce stigma. Special care should be taken to protect the human rights of people with dementia and regulate the status of family members who are at risk of burnout and often fall ill themselves. Special attention should also be given to the prevention of violence against people with dementia and the empowerment of people with dementia and their families (carers) in society.

The Glasgow Declaration defines the human rights of people with dementia and binds its signatories to fulfil them. These rights are:

- the right to a timely diagnosis,
- the right to access quality post-diagnostic support,
- the right to person-centred, coordinated, quality care,
- the right to equitable access to treatments and therapeutic interventions,
- the right to be respected as an individual in their community.

2.5.2 Convention on the Rights of Persons with Disabilities

WHO considers dementia to be a major cause of disability among adults. This means that dementia is a great handicap for a person. EU Member States also expressed a clear conclusion that dementia must be recognised as a disability. Therefore, in designing the legal framework that defines the rights of people with handicaps and covers care, treatment, therapies and research, people with dementia must be considered people with handicaps and with a disability.

The understanding of disability should consider the person and the environment in which this person lives. People with dementia are people with handicaps, which are a result of their psychophysical condition and the unadapted environment. All rights guaranteed by the Convention on the Rights of Persons with Disabilities apply to people with dementia, regardless of whether the person concerned has a status of a person with disability under the Slovenian legislation.

Due to the nature of the disease, it is important to be aware of cultural differences and to understand and identify people's spiritual and existential needs. Appropriate knowledge must be obtained to work with people with dementia from other ethnicities and national minorities and their families. Alzheimer's Disease International and Alzheimer Europe recommend[22] that a supporting environment for intercultural care be developed. This is an important part of a just society in which people with dementia and their carers can have a good quality of life regardless of their cultural background.

[22] Alzheimer Europe. Intercultural dementia care for health and social care providers: a guide. Policy briefing on intercultural care and support for people with dementia and their informal carers/supporters, 2020

3. KEY PRIORITY AREAS

3.1 The establishment and maintenance of a set of epidemiological data on dementia in Slovenia

Public health surveillance is the ongoing, systematic collection, analysis, interpretation and dissemination of data regarding a health-related event to be used in public health action to reduce morbidity and mortality and to improve health.[23] The evaluation of epidemiological surveillance gives an insight into the applicability and characteristics of the system (data quality, representativeness, sensitivity, simplicity, acceptability, timeliness, stability, flexibility, positive predictive value). The epidemiological surveillance of dementia in Slovenia is not yet such to enable reliable estimates based on routine health databases. The surveillance system has also not been evaluated yet.

The purpose of a national register of people with dementia is to keep a record of the number and characteristics of people with dementia. A large set of the data collected will enable a comprehensive overview of the situation at the city, regional and national levels. Any changes will be recorded annually to follow trends in the treatment of the disease in individuals and large sub-groups. The register will give accurate data on the number of people with dementia, the share of types of dementia, and the demographic and diagnostic characteristics of patients by regions. This will give a good general overview and facilitate the improvement of the treatment of people with dementia, as the data will enable treatment adaptation. A national register will also enable an indirect calculation of cost estimates and the adjustment of national health economic policies for dementia.

The WHO Global Action Plan states that by 2025, 50% of countries should routinely collect a core set of dementia indicators for epidemiological surveillance of dementia through their national healthcare, long-term care and social assistance information systems. The basis for establishing an electronic national register for dementia surveillance is an amendment to the Healthcare Databases Act.

With regard to the Strategy bases, the relevant action plan will also define the content, implementation and organisation of the national dementia register.

3.2 The network of providers of programmes and services for people with dementia and their families

The Strategy for Dementia Management plans actions to improve the method of raising public awareness of dementia and preventive activities, and the access to an early diagnosis and appropriate post-diagnosis treatment of people with dementia by strengthening the integrated network of programme and service providers and improving the network's organisation. Continuous education must be provided for everyone working in the field of dementia, including patients' families, and it must include specialised knowledge for particular professional groups. The network includes public services at all healthcare, long-term care and social assistance levels, and is supplemented by non-formal and user organisations and associations active in the field of (mental) health and other associations, organisations and individuals supporting social inclusion and health promotion in local communities.

Programmes and services for people with dementia and their families are divided based on the provider into:

1. healthcare services and programmes,
2. social assistance services and programmes,
3. community-based services and programmes (integrated long-term care, social assistance and healthcare services),
4. activities of NGOs and informal carers.

[23] Centers for Disease Control and Prevention. Updated Guidelines for Evaluating Public Health Surveillance Systems. MMWR 2001; 50 (No RR-13).

The listed services and activities are often combined.

Cross-sectoral cooperation is the key to ensuring a comprehensive and coordinated response by public institutions, education systems, employment and infrastructure, and the establishment of links between the civil society and private undertakings. The cooperation and integration of different sectors will be further strengthened.

3.2.1 Healthcare services and programmes

Dementia is caused by a brain disease and is not part of normal ageing. It is essential that the disease be detected as early as possible and treated appropriately. Dementia's development can be slowed down, the disease managed and negative impacts on patients and their immediate and wider surroundings prevented with a timely identification and treatment of the disease. Good cooperation within healthcare and integration with other services and stakeholders in the local environment are essential for this.

In 2022, Slovenia had 64 community health centres, 26 hospitals (of this, 4 psychiatric hospitals) and 2 clinical centres. The services at the tertiary and secondary levels are provided by the Centre for Cognitive Impairments at the Neurology Division of the University Medical Centre Ljubljana (hereinafter: UMC Ljubljana). There is also the Geropsychiatric Unit of the University Psychiatric Clinic Ljubljana. At the University Medical Centre Maribor (hereinafter: UMC Maribor), secondary and tertiary level services are provided by the Department of Neurology and the Department of Psychiatry with the Geriatrics Unit. Psychiatric hospitals also have geropsychiatric units.

Care homes are social care institutions and provide family medicine clinics for their residents. Under the medical care standard, residents are entitled to a family medicine team.

Unlike the majority of developed countries, Slovenia has no medical specialists in geriatrics and no healthcare providers with specialist gerontology knowledge. There is currently only one centre for geriatrics, which is at the Division of Internal Medicine of the UMC Ljubljana.

3.2.1.1 Primary healthcare

Primary healthcare is the basis of healthcare, which includes dementia management, as the majority of people with dementia are treated by their chosen personal doctor. A family doctor is the first contact of a person with suspected dementia. Family medicine clinics also include referential clinics for managing stable patients with chronic diseases.

The Resolution on the National Mental Health Programme 2018–2028 (ReNPDZ18–28) introduces mental health reform and transfers the core of treatment to primary healthcare. A network of 25 centres with mobile teams for adult mental health is being set up within community health centres.

Each community health centre has a health education centre. In recent years, 25 health education centres have expanded their work programmes and were converted into health promotion centres.

Primary healthcare includes the community nursing service, whose role in the treatment of older people is often overlooked. The community nursing service can play an important role in prevention, as it carries out both curative and preventive activities. There are 756 community nurses working in the field. They are organised by territory.

3.2.1.1.1 Family medicine clinics

In 2021, the public healthcare network included 967.89 family doctor teams working at 64 community health centres or at private family medicine clinics with concessions.

At the primary level, a family medicine clinic is the point of first contact with a person with dementia and their family. It takes care of the person with dementia for the duration of the disease, until the end of their life. The clinic's doctors also take care of people with dementia living in care homes.

The clinic carries out comprehensive treatment of people with dementia – a team of one family doctor, one healthcare assistant and 0.5 registered nurses is in charge of disease detection, treatment diagnostics and long-term follow-up of the person with dementia. The important elements of dementia treatment are early identification of the disease, diagnostics with the exclusion of reversible dementia, medical treatment and long-term follow-up. A person with suspected dementia is referred to a specialist in neurology or psychiatry for further diagnostics, diagnosis confirmation and medical treatment.

Dementia requires a specific approach, as families and other specialist services are included in the treatment from the very beginning. The majority of people with dementia live at home and the treatment is provided by outpatient clinics. After diagnosis, in addition to the family doctor, the treatment chain includes visiting specialists, such as community nurses, social workers and specialist staff from other social care services. The timely planning of long-term care and good cooperation of all stakeholders with the family improve the effectiveness of care and the quality of life of the person with dementia and their family, so that the person with dementia can stay in home care longer. Modern forms of information technology should promote a multidisciplinary approach and facilitate the integration of family doctors, specialists and visiting specialist services.

Prevention represents an important part of family medicine and was formally included in the work of family medicine clinics by the inclusion of registered nurses in family medicine teams, who take care of the identification of risk factors for chronic diseases and the management of chronic diseases. The prevention programme includes the most common chronic diseases with the relevant screening tests for detecting risk factors and measures to eliminate risk factors. At present, dementia is not included in the detection and management programme implemented by chosen personal doctors. Chronic diseases often overlap. Currently, risk factors for cardiovascular diseases, which are also an important risk factor for vascular dementia, are being surveilled. Considering the increasing number of older people and people with dementia in society, the family medicine programme must be supplemented and dementia must be included in the chronic disease management programme at the primary level, which will improve the quality of treatment of people with dementia and enable epidemiological surveillance. Recent studies have discovered new dementia risk factors, such as hearing impairment, arterial hypertension during middle age, depression, obesity, smoking and air pollution, and warn of the effect of non-cognitive biomarkers, such as sleep disorders, walking disorders and parkinsonism symptoms. These markers will improve the preventive approach to dementia treatment and prevention.

The shortage of family doctors is slowing the introduction of changes in dementia treatment necessary to effectively manage people with dementia in a home environment. The network of family medicine clinics and the community nursing service must be strengthened.

3.2.1.1.2 Health education centres and health promotion centres

Health promotion centres are an upgrade of health education centres that used to operate within community health centres. The programmes of health promotion centres are closely related to the prevention activities of family medicine clinics. They are intended for the entire population and aim to promote and educate for a healthy lifestyle and risk factor prevention. The programmes are implemented through lectures, workshops and individual consultations on health promotion. They also address mental health, for example, how to deal with depression and anxiety. The inclusion of workshops on dementia identification and psychosocial support for families dealing with dementia in the programmes of health

promotion centres will contribute to the prevention of depression and burnout in families and to dementia management in the home environment.

3.2.1.1.3 Adult mental health centres (with mobile teams)

Adult mental health centres are a new organisational structure at the primary level and an upgrade of mental health centres. These centres will be organised on a regional and multidisciplinary basis and will improve the accessibility of psychiatric services. They will provide assistance and support to all adults with mental health difficulties. In total, 25 such centres with mobile teams are planned in Slovenia. They will provide primary, secondary and tertiary services for prevention, early treatment of adults at risk of mental health difficulties and specialist treatment of mental health difficulties. They will operate on a multidisciplinary basis and in accordance with the principle of approximation of mental health services to people's primary environment. They will enable the examination and treatment of persons in their home environment. Centres will adjust the measures to the individual's needs.

By co-designing the programmes of these centres it must be ensured that people with dementia and their families have access to their services, i.e. cognitive stimulation and rehabilitation programmes for people with dementia and psychosocial support programmes for their families.

By 2022, Slovenia had set up 16 such centres with mobile teams. Due to the shortage of qualified staff, some of them are still operating with incomplete teams.

3.2.1.1.4 Community nursing service

The community nursing service is a constituent part of primary healthcare and is normally organised on a territorial basis. According to the National Institute of Public Health (NIJZ), in 2021 Slovenia had 756 community nurses and 98 healthcare assistants.

Community nursing treats patients at their homes. In addition to medical care, the service performs prevention work focused on treating families in the environment and community throughout their lives, and in particular on providing care to people over 65 years, identifying social assistance needs, particularly vulnerable groups, violence and addiction.

Dementia affects both the person with dementia and their entire family. A community nurse should, therefore, meet with the family immediately after the diagnosis. As the disease is long-lasting and progressive, a community nurse follows up the person with dementia and their family for years and responds to their needs as the disease progresses. To provide effective support, community nurses need wide and diverse knowledge in caring for people with dementia. They must be enabled to regularly improve their knowledge on dementia. An increase in the number of community nurses and the inclusion of specialist dementia community nurses would upgrade the community nursing service and improve the treatment of people with dementia in the field.[24]

3.2.1.1.5 Integrated care

After the project "Implementation of pilot projects that will support the transition to the implementation of a systemic law on long-term care", in which new integrated solutions were tested for the long-term care of people older than 18 years who are permanently dependent on the assistance of others, was concluded in 2020, a concept of integrated home care was set up in the Municipality of Krško. This is a system of measures, services and activities intended for those who, due to diseases, frailty associated with old age, injuries, disabilities, or lack or loss of intellectual capacities, are for an extended period of

[24] In 2019, the community nursing service treated 1,570 persons with mental and behavioural disorders (F00-F99), which represented 2.7% of the visits, and 1,612 patients with diseases of the nervous system (G00-G99). NIJZ. Zdravstveni statistični letopis Slovenije, 2019, https://www.nijz.si/sl/nijz/revije/zdravstveni-statisticni-letopis-slovenije.

time or permanently dependent on others for assistance with basic and instrumental activities of daily living. The municipality undertook to provide these services for the next two years. In collaboration with other institutions, the municipality will provide for the upgrade of home help services, which can effectively alleviate personal distress and prevent greater dependencies which lead to the overload of the healthcare and social assistance system and overburdening of informal carers. The main contribution is the provision of services for maintaining independence, which means that people with dementia are treated by occupational therapists, physiotherapists and nursing staff who ensure the quality of their life and enable them to live longer in their home environment.

Long-term care entry points must be included in the integration of the above-mentioned services. As part of the project "The redesign of the existing networks and inclusion of new providers of community-based services and programmes for adults and older people", a screening test was added at entry points to determine deviations in the population of older people who believe they need assistance, support or services in performing day-to-day activities. The assessment according to the long-term care rating scale provided by the Long-Term Care Act includes an option to check the incidence of deviations and the consistency between the two scales used.

The treatment of people with dementia is part of long-term care treatment, as dementia is a chronic progressive disease, which in different stages requires support and services adapted to the needs of the individual.

More than two thirds of people with dementia live at home, in the care of their families. These are usually spouses and children, who by taking care of a person with a progressive disease face special medical, social and financial challenges. Compared to the general population and the carers of people with other diseases, they are in poorer physical health and under greater mental stress. An interdisciplinary system of home help must be set up within the integrated treatment (appropriate time norm, multidisciplinary teams, reports, follow-up visits, transfer of information between social assistance and healthcare providers).

In the coming years, we will strive to develop and establish a network of memory centres, in which targeted early diagnostics and treatment will be set up for a wider area within a multidisciplinary treatment including health, social affairs, psychology, pedagogy and other fields.

3.2.1.1.6 Palliative care

Good palliative care of people with dementia must be provided in the environments in which they live. Palliative care of people with dementia is complex, as cognitive ability in later stages of dementia is usually so impaired as to limit communication. It is prudent to include palliative care principles early in the treatment, in accordance with international guidelines and recommendations of medical experts on the correct identification of disease milestones and assessment of symptoms. People with dementia also need more social and nursing care. Their families who often take on the role of their carers and have to make difficult decisions must be included in the treatment.

The basic palliative support is provided by the chosen personal doctor and a community nurse or, in care homes, the care home's doctor and multidisciplinary team. The nursing and social support in the home environment is provided within the home help system under the Long-Term Care Act. If necessary, a psychiatrist will be included in the medical treatment at home, who can examine the person at home as part of the community-based psychiatry or the mobile team of the adult mental health centre. This is particularly useful in the case of resistant, agitated or immobile patients.

Specialist palliative support is provided by mobile palliative care units in the home environment and by palliative care departments or units in hospitals. The referral to a specialist palliative care level is made in accordance with the relevant criteria.

3.2.1.2 Secondary and tertiary healthcare

Secondary and tertiary healthcare in Slovenia is provided by 26 hospitals, including the UMC Ljubljana Division of Neurology, the UMC Maribor Department of Neurological Diseases, four psychiatric hospitals, the UMC Maribor Department of Psychiatry and the University Psychiatric Clinic Ljubljana. At these levels, there is considerable overlap between neurology and psychiatry. Neurologists primarily treat patients suffering from dementia in subspecialist cognitive neurology outpatient clinics at the tertiary level, and they provide diagnostic treatment for dementia or its earlier stages through day hospitals and short inpatient stays (including biomarker analysis and advanced brain imaging). Psychiatrists provide treatment for dementia in both specialist outpatient clinics and hospitals. In addition, regional general hospitals have neurology divisions that provide specialist outpatient services.

In accordance with the ReNPDZ18–28, a new standard for geropsychiatry has been adopted for specialist geropsychiatric centres and units that focus on specialist inpatient treatment of acute mental disorders or conditions in old age, in particular dementia.[25]

The Centre for Cognitive Impairments at the Clinical Department for Diseases of the Nervous system at the UMC Ljubljana Neurology Division receives patients with suspected neurocognitive disorders of varying severity, ranging from subjective cognitive complaints to mild cognitive impairment and dementia, who are referred from family medicine outpatient clinics and other specialist outpatient clinics.[26]The primary role of tertiary care institutions is to provide comprehensive diagnostic and therapeutic treatment for people with dementia, to support their carers and to establish good partnerships with social services, other health institutions and voluntary associations.

A systematic clinical pathway for the treatment of patients with cognitive impairment has been established at tertiary level institutions in 16 regular cognitive outpatient clinics, one diagnostic day hospital and as inpatient treatment.[27] At the UMC Maribor Department of Neurologic Diseases, patients with cognitive impairment are regularly treated by neurologists and clinical psychologists as part of hospital treatment and subspecialist outpatient examinations. The clinic has developed a clinical

[25]Dementia syndrome is caused by a neurodegenerative brain disease in approximately 80% of cases, while in the remaining cases it is a potentially reversible condition of other etiologies. The clinical symptoms of a disease leading to dementia syndrome vary widely, and their recognition and interpretation require focus and expertise in neuroanatomy, neuropathology, genetics, and related fields; based on such expertise, a specialist neurologist and/or psychiatrist carefully evaluates the individual's clinical picture, individual characteristics and underlying health conditions. Etiological differentiation between the various types of dementia can be particularly challenging, especially in the early stages of cognitive decline (subjective cognitive complaints and mild cognitive impairment) and in the early stages of dementia. In the early stages of the disease, comprehensive neurological and/or psychiatric diagnostic treatment and follow-up are critical for accurate diagnosis, prognosis and assessment of the impact on the quality of life of the individual and their family and, importantly, the economic and social burden on society as a whole.

[26]The core activity of the centre is to provide specialist team treatment at the secondary and tertiary levels for patients in the early stages of cognitive decline who have not yet reached the dementia stage, as well as for atypical, reversible or rapidly progressive dementias, those occurring in younger patients, or those associated with other neurological, primarily neurodegenerative disorders.

[27] This routine multidisciplinary work involves neurologists, psychiatrists, clinical psychologists, neuroradiologists, specialist graduate nurses, social workers, clinical speech therapists, occupational therapists and physiotherapists. The cerebrospinal fluid (CSF) laboratory at the Clinical Section for Diseases of the Nervous System under the UMC Ljubljana Neurology Division has introduced a standardised and European harmonised analysis of the CSF biomarkers for dementia. The clinic also routinely uses functional and advanced structural brain imaging techniques to diagnose dementia. Similarly, standardised CSF biomarker analysis and basic and advanced brain imaging techniques (FDG-PET-CT, PET-CT imaging with amyloid markers) are also used at the subspecialist neurological cognitive outpatient clinic, Department of Neurology, Department of Nuclear Medicine, the University Medical Centre Maribor and as part of inpatient care.
Regarding the neurological profession, a multidisciplinary team for patients with cognitive impairment is currently in place and funded only at the Centre for Cognitive Impairment, UMC Ljubljana. Regrettably, the team dedicated exclusively to patients with cognitive impairment is very small (2 neurologists, 1 psychiatrist, 1 nurse, 1 clinical psychologist and 1 administrative worker). The duties and responsibilities of most of the multidisciplinary team members are distributed among other routine and specialist neurological duties, which limits the capacity to fully focus on cognitive impairment care.

pathway for the diagnostic treatment of patients with cognitive decline and has standardised cerebrospinal fluid diagnostics and imaging diagnostics (CT, MRI and PET-CT). The clinic is also actively involved in the education of medical students from the Faculty of Medicine, University of Maribor, nursing students from the Faculty of Health Sciences, University of Maribor, and international students through the Dementia Knowledge Exchange Programme. In addition, the clinic mentors residents in psychiatry, neurology and family medicine as part of their residency training programme. Its neurologists are also involved in educating the general public through lectures and articles published in the popular literature.

In line with the Strategy's guidelines, it is necessary to reinforce the organisational, spatial and human resources needed to support the work of the multidisciplinary team, both within the neurological clinics of the two main medical centres (Ljubljana and Maribor) and in other regional general hospitals where neurological treatment of patients with cognitive impairment is already provided.

Slovenian neurologists (in Ljubljana, Maribor and Nova Gorica) with additional expertise in dementia participate in international clinical trials in dementia. Members of the Centre for Cognitive Impairments at the Clinical Department for Diseases of the Nervous System at the UMC Ljubljana Neurology Division engage in the development and implementation of educational programmes at the Faculty of Medicine. Several research projects in the field of dementia are being carried out within this centre.

The University Psychiatric Clinic Ljubljana treats patients with dementia and related mental disorders in both inpatient and outpatient settings. The majority of people with dementia who are admitted to hospital have associated behavioural and psychological problems. The Geropsychiatric Unit at the University Psychiatric Clinic Ljubljana has five inpatient wards (total of 90 beds), one day care ward and eight geropsychiatric outpatient clinics dedicated to the diagnosis and treatment of dementia and other mental disorders in older adults. The unit also provides key training in dementia for medical students at the University of Ljubljana's Faculty of Medicine and mentors residents in psychiatry, neurology and family medicine as part of their residency training programme. It also provides valuable support and training for family members of people with dementia, including organising a support group for family members.

The University Medical Centre Maribor has a geropsychiatric unit with 36 beds. In addition, other psychiatric hospitals provide geropsychiatric care with 34 beds in Idrija, 17 in Begunje, 20 in Ormož and 15 in Vojnik. The geropsychiatric units in psychiatric hospitals are dedicated exclusively to the treatment of acute mental disorders and conditions in the elderly, with both intensive and open wards. The psychiatric hospital in Idrija also has a team for specialist outpatient geropsyhiatric treatment.

In psychiatric hospitals, patients with dementia are usually treated in open wards. However, if a patient's health is seriously compromised because of dangerous behaviour or if the patient is a danger to themselves or others, they are treated in wards under special supervision. Before a patient is discharged from hospital treatment, an individualised psychosocial rehabilitation plan is usually drawn up, either for the patient's home environment or for transfer to a social care facility. To implement this plan, the competent hospital services coordinate with family members, the patient's personal doctor, social work centres, community care coordinators and other stakeholders involved in the patient's psychosocial rehabilitation or transfer. If people with dementia are unable to return to their home environment for health or social reasons, arrangements are made to transfer them to a social care facility. Those who return home receive regular outpatient follow-up after discharge.

In line with the Strategy's guidelines, an efficient service chain for people with cognitive impairment needs to be established, ensuring seamless integration of services and healthcare capacities at all levels. This will be achieved by implementing the Strategy's goal of establishing a polycentric network of memory centres with staffing standards for interdisciplinary, team-based treatment and care of people with dementia in line with current clinical trends.

3.2.1.3 Healthcare provided by social care institutions

The healthcare system provides medical care to residents of care homes, with [28]a chosen personal doctor available on-site. On average, a general family practice team at an outpatient clinic is responsible for 306 residents. In 2020, the Health Insurance Institute of Slovenia contracted 71.21 healthcare providers. The current standard for medical care allows for one specialist doctor per 2,000 beds, or 0.0005 specialists per bed per day. This figure is insufficient to meet the actual needs and therefore the standard should be revised to better reflect the required level of care.

3.2.2 Social assistance services and programmes

In developing social assistance services and programmes, the main objectives are to increase the proportion of users receiving community-based assistance, adapt services to meet the diverse needs of target groups, ensure the accessibility and availability of services, expand the range of service options, strengthen the staffing of providers, modernise infrastructure and create a dementia-friendly environment for people with dementia. Providers should receive regular education and training based on modern approaches to working with people with dementia.

While the expansion and development of the network of providers of social assistance programmes and services are set out in the ReNPSV22-30, the achievement of these objectives will also depend on the adoption of new legislation, i.e. systemic regulation in areas such as long-term care, deinstitutionalisation and the reorganisation of provider networks.

3.2.2.1 Institutional care for the elderly: care homes

At the end of 2021, there were 103 providers in the public network with 19,206 places for older adults and 2,367 places for special groups of adults. The average age of care home residents is 83 years, with an estimated 70% of older residents living with dementia at various stages of the disease.

The ReNPSV22-30 aim is to have 4.5% of older adults aged 65 and over in institutional care, with future plans for institutional care providers to also expand their role to provide community-based services. Activities are underway to ensure appropriate standards for a friendly and safe living environment, especially in terms of infection control, to be funded in the future by both EU funds and national budgets. In addition, as part of the modernisation of social infrastructure, three community centres for people with dementia will be established with EU funding from the European Regional Development Fund.

In institutional care for the elderly, the number of beds and specialist units for people with dementia needs to be increased. Facilities and staff also need to be adapted to implement modern approaches to working with this target group. Institutional care providers will also expand their activities by providing community-based services (day centres, respite care options, smaller residential units) tailored to the needs of people with dementia. Greater emphasis should also be placed on the provision of palliative care. Existing guidelines for working with people with dementia should be supplemented with specific guidelines for the care of younger people with dementia (e.g. special units) and guidelines for care during infections.

Institutional care for adults with intellectual disabilities

In 2021, 5,322 adults were provided with services by care and work centres as well as centres for training, work and care, of whom 10% of people with dementia, according to estimates by individual providers. It is therefore necessary to adapt individual residential units to meet the needs of people with

[28] In 2020, 3,671 healthcare workers were employed in social care institutions to provide healthcare to 21,969 people (19,296 people in care homes, 1,560 people in special institutions for adults and 1,113 people in care and work centres) (source: Ministry of Labour, Family, Social Affairs and Equal Opportunities).

dementia and to ensure that both facilities and staff are equipped to implement modern care approaches for this target group. In addition, efforts must be made to improve the education and training of staff, while providing counselling and support to parents, legal representatives or guardians of people with intellectual and physical disabilities, including those with dementia.

3.2.2.2 Day care and short-term (respite) care options

Day care services are intended for people who do not yet need full-day care but who benefit from an organised form of stay for a few hours a day. In 2021, institutional care providers offered 607 day care places for older adults, with demand for this service growing, especially in urban centres. Day care is often accompanied by organised transport.

The ReNPSV22-30 aims to expand this service by providing about 1,300 day care places for the elderly. These places will include tailored day care services for people with dementia, available daily in all Slovenian regions, with transport provided.

There is also an increasing demand for short-term (respite) care. This service is very important for people with dementia and their families, and will need to be significantly strengthened in the future to meet the growing demand.

3.2.2.3 Home help

In 2021, 12,921 people benefited from home help services, with a notable increase in users aged 80 and over, who accounted for 67.6% of the total at the end of the year. In addition, 64.4% of users received less than 3.5 hours of help per week. Despite the legal obligation for municipalities to provide and subsidise this service, in 2021 only 27 municipalities exceeded the 3% inclusion target for older people aged 65+ set by the ReNPSV22-30.

Home help is a vital support service for people with dementia and their families, enabling them to remain in their home environment. Home help needs to be made more accessible by increasing the number of outreach services and by improving and adapting their content specifically to people with dementia. Efforts should also be made to standardise pricing, extend the availability of services to all days of the week, and improve access to ICT services for people with dementia.

SOCIAL ASSISTANCE PROGRAMMES

People with dementia also need other forms of support, many of which are already successfully provided through social assistance programmes. These include psychological support, advocacy, information offices, education, counselling, volunteer services, self-help groups and activities for those still living at home (structured daily activities, memory training, maintaining social and motor skills and so forth). The ReNPSV22-30 aims to strengthen the network of social assistance programmes focused on work with older people and people with dementia, both in the community and in their homes.

Social work centres (SWCs)

Social work centres play a crucial role in providing advice and support to people with dementia, their families and carers. In recent years, there has been a significant increase in activities to provide various forms of assistance to people with dementia (counselling, legal exemptions, handling cases of deprivation of legal capacity, appointing guardians in special cases, finding emergency accommodation and so forth). It is therefore essential to provide regular training for the staff of social work centres on how to recognise dementia and how to communicate effectively with people suffering from dementia. Adequate support also needs to be provided to professionals in dealing with people with dementia.

3.2.3 Community-based services and programmes

Community-based services help people to remain in their home environment longer and prevent social exclusion. These services are made available by a range of providers, including public community-based services, private individuals, private providers with concessions, family members and NGOs. The key to success is the inter-ministerial integration of all stakeholders into a cohesive network of healthcare and social care services. This approach ensures optimal interdisciplinary and inter-ministerial consideration tailored to the needs of individuals and their communities (ReNPSV22–30).

One of the crucial forms of support often lacking for people with dementia and their families is post-diagnosis support through an individualised, team-based approach involving a healthcare professional, psychologist, social worker, occupational therapist, legal advisor and financial advisor. Post-diagnosis support should include psychological support, information, education, counselling and volunteers for various support groups, including groups for people with dementia. People with dementia living at home should be provided with services to improve and maintain their cognitive abilities, to foster independence, and to promote community and social inclusion as defined in the Long-Term Care Act.

It is equally important that social assistance and home care services are available for people with dementia under the age of 65 (according to Alzheimer Europe, there were an estimated 1,939 people with dementia aged 30-64 in Slovenia in 2018). These services should be person-centred and provide personalised care throughout the progression of the disease, with consideration given to any pre-existing or emerging medical conditions that may arise during the course of the disease.

Community-based services and programmes are characterised by an interplay between social and healthcare services, while also recognising the important role of family members, informal carers, and other stakeholders in creating a dementia-friendly environment. Self-help groups and humanitarian organisations, which have both staff and financial resources to carry out their activities, also have a very important role to play. Their activities complement those of the public health and social care network.

3.2.4 Activities of NGOs and informal carers

NGO activities are well established in Slovenia. Humanitarian organisations and NGOs play a crucial role in society in providing help and support to people with dementia and their family members, as well as giving people with dementia a voice in society, a need that will only grow as the number of people with dementia increases in the future. From a community-based care perspective, NGOs are an important societal pillar in dementia management, creating a stable system of established organisational structures that involve all relevant actors. Their efforts to raise awareness and reduce stigma are particularly important to ensure timely diagnosis of people with dementia. To this end, a network of Dementia-Friendly Points across Slovenia has been established, involving a wide range of organisations.

In Slovenia, several NGOs focus on mental health and neurological diseases, with Spominčica - Alzheimer Slovenija standing out as the main organisation dedicated to dementia. Founded in 1997 to support the family members of people with dementia, Spominčica is a vehicle for raising awareness about dementia and providing training and education to carers of dementia patients. It offers support and empowerment to their family members, who often face severe psychological, physical, emotional and financial burnout and social exclusion during this long-term illness. Spominčica is the founder and coordinator of the national Dementia Friendly Points network, which provides local access to information, training, support and knowledge sharing. Informed, trained and well-supported family members can significantly improve the quality of life for both the person with dementia and themselves, allowing people to remain in home care for as long as possible – a more humane and ethical approach.

Spominčica also plays a key role in uniting dementia professionals across Slovenia and is actively involved in numerous international collaborations.

Globally and in Slovenia[29], women are the main providers of informal care for family members with chronic illnesses, including the elderly and adults with dementia[30]. As a result, they are at higher risk of burnout, depression and other health issues. It is expected that the number of carers, especially women, for people with dementia will continue to increase. In addition, women are more likely to develop dementia-causing diseases and tend to seek help later. The status of carers of people with dementia in the home setting should be regulated and supported by an adequate and high-quality range of community-based care services.

There are also other associations in Slovenia that help patients and family members of people with brain disorders whose clinical picture may include dementia (the Trepetlika Association - the association of patients with parkinsonism and other extrapyramidal disorders, the Huntington Association of Slovenia, the Slovenian Stroke Association and more).

In healthcare and social care, the state should provide more stable funding for programmes run by humanitarian organisations that meet the relevant quality standards and complement the public health and social care network. NGOs must meet these quality requirements and follow integrated care practices to provide comprehensive support.

[29]According to estimates by Mag. Ksenija Ramovš and the Anton Trstenjak Institute, more than 30,000 people in Slovenia already receive informal care at home.

[30] The volume of informal care is estimated at around 82 billion hours, 71% of which is provided by women. In almost all EU Member States, more than 50% of carers under the age of 65 combine employment with the demands of providing care at home. The gender gap in this context is significant, with many women either leaving the paid workforce or reducing their hours to part-time in order to provide care. In Europe, only 50% of women who are informal carers are able to maintain full-time employment.

4 QUALITY AND SAFETY ASSURANCE

The Strategy supports the implementation of a comprehensive national concept aimed at ensuring the quality and safety of healthcare services. Ensuring high quality and safe treatment of people with dementia, while making efficient use of resources, requires careful planning and implementation of processes. This includes the establishment of national clinical practice guidelines, individualised clinical pathways and effective process management. To assess and improve the quality and safety of dementia treatment at the primary level, it is essential to develop tools that promote an integrated approach to treatment. Continuous quality and safety of treatment and its improvement at all levels of healthcare should include quality monitoring based on clinical expertise, the experiences of people with dementia and their families, and the results of treatment. It is important to ensure that treatments remain in line with advances in the field. Quality monitoring and evaluation should aim to improve the safety and quality of dementia treatment for both patients and healthcare providers, fostering a strong culture of safety. Achievement of quality and safety improvement goals should be evaluated at multiple levels, including healthcare providers, management and educational institutions.

Changes in leadership and management, as well as the provision of resources (skills and infrastructure, including IT support and financial resources) are also crucial for the successful implementation of the national concept for the system of quality and safety. Effective coordination and support of quality programmes should be ensured, with the introduction of various incentives to promote a change in the mindset of the leadership and those responsible for establishing a comprehensive framework for quality and safety in healthcare. Incentives, advanced knowledge, skills and tools must be provided to enable managers to drive the necessary changes in order to effectively manage overall quality and safety. Staff development and continuing education should be an integral part of the management process, as experience has shown that this approach leads to improved performance, efficiency, professionalism, and the overall quality and safety of treatment.

Professional associations will review and update, as appropriate, clinical practice guidelines and clinical pathways within six months of the adoption of the Strategy, to ensure appropriate quality and safe treatment of people with dementia. Clinical practice guidelines and pathways will be regularly reviewed and updated at least every three years.

4.1 Clinical practice guidelines and pathways for quality and safe treatment of dementia

Clinical practice guidelines and recommendations for the treatment of people living with dementia provide evidence-based support for physicians, healthcare professionals and other specialists working with dementia patients. These guidelines aim to ensure quality treatment and to standardise care practices. They should cover key aspects such as recommendations for the diagnosis, treatment and quality long-term care of people with dementia, while addressing legal and ethical issues that may affect the quality and safety of treatment.

In Slovenia, the applicable guidelines for the treatment of dementia provide a framework at the primary care level. These guidelines include diagnostic criteria, [31]guidelines for the management and medical treatment of cognitive and behavioural symptoms and disorders that may accompany dementia, emergency measures, and a review of recommended medications with prescribing indications and recommended effective doses. However, in light of ongoing developments in the field, it is appropriate

[31] Darovec, Jože, Kogoj, Aleš, Kores-Plseničar, Branka, Muršec, Mojca, Pišljar, Marko, Pregelj, Peter and Stokin, Gorazd Bernad. Guidelines for the treatment of patients with dementia, Zdravniški vestnik, Year 83, No. 7/8, po. 497–504.

to update the guidelines with recent advances in the diagnosis and treatment of cognitive decline, following the NICE[32] guidelines on dementia and other relevant sources.

It is also important to develop tailored clinical pathways for the safe and high quality treatment of people with dementia at both primary and secondary healthcare level in individual health institutions, taking into account integrated care in both inpatient and [33]outpatient settings. Clinical pathways should be regularly updated in line with guidelines or new evidence-based developments in the diagnosis and treatment of dementia.

4.2 Cooperation protocols

Effective dementia treatment relies on seamless cooperation between all services involved in and organised to support people with dementia. It is therefore essential to prioritise the development of integrated treatment at the primary healthcare level—within communities and home settings. High quality, timely, comprehensive and accessible treatment of people with dementia requires a coherent interdisciplinary network of services, programmes and facilities to provide them with optimal care as quickly as possible, and to avoid both duplication and gaps in services. Given the diverse needs of people with dementia and their family members, treatment should be personalised. Cooperation protocols will facilitate effective planning and cooperation between services.

Cooperation protocols between services within the same or different sectors allow for continuity of treatment throughout the care pathway, from prevention to treatment, psychosocial rehabilitation and palliative care. The aim of these protocols is to increase access to dementia management services, improve the efficiency and continuity of treatment throughout the care pathway, ensure coordination and (co)operation of services or service providers, and improve the quality and safety of services. They also aim to reduce the stigma surrounding dementia and combat ageism. These protocols provide staff with essential guidelines to follow in their daily work, as well as a formal framework for linking services and service providers. By detailing the working methodology and structure of service providers, the protocols facilitate cooperation between professional services within one sector or across multiple sectors. They also promote cooperation with people with dementia, their family members and other stakeholders who can contribute to the management of dementia and the creation of dementia-friendly environments. A detailed description of the cooperation protocols is also provided to give people with dementia, their family members and members of the public with an interest in this a broader insight into the way each service works.

[32] Dementia: assessment, management and support for people living with dementia and their carers, NICE guideline (NG97), published on 20 June 2018, https://www.nice.org.uk/guidance/ng97.

[33]The following documents are currently applicable and in use at the University Psychiatric Clinic Ljubljana:
– Clinical pathway for the treatment of patients with dementia (in day care);
– Clinical pathway: Initial risk assessment for dementia on admission;
– Clinical pathway for review in geropsychiatric examination; and
– Frailty clinical pathway.

The following documents are currently applicable and in use at the UMC Ljubljana Division of Neurology:
– Clinical pathway for the treatment of patients with mild cognitive impairment; and
– Clinical pathway for the treatment of patients with dementia.

5 HUMAN RESOURCES

To achieve the goals set, it is essential to have effective promotion and staff planning policies in place to ensure a sufficient number of appropriately trained health professionals and colleagues from other disciplines. These multidisciplinary teams must be able to provide comprehensive and high quality treatment to patients.

In order to ensure the successful operation of teams and integrated treatment, it is crucial to optimise the work of all providers within the healthcare and social assistance system and to integrate them seamlessly into the long-term care framework for the holistic treatment of patients. This includes reducing administrative burdens to free up more time for direct work with a dementia patient. Legislation should be enacted to regulate, enable and facilitate the delegation of certain responsibilities and tasks, currently performed by staff in short supply, to other qualified professionals. In this regard, Slovenia can draw on best practices from other European countries, such as Finland or the United Kingdom and the Netherlands, which have implemented the concept of a specialist dementia health visiting service.[34]

Strategic and effective policies, along with appropriate working conditions, need to be put in place to prevent burnout among health and social care workers. Staff should be provided with upskilling and training, particularly in working with people with dementia. This training should include key areas such as effective communication, conflict management and the recognition of all forms of violence.

To mitigate the effect of staff shortages, an action plan will be developed to include short- and long-term measures to increase staff competencies. Long-term measures include training for shortage occupations and the systemic introduction of additional training or specialisation in working with people with dementia. Short-term goals to alleviate the staff shortages include additional training for current staff and measures to increase dementia literacy among the general and target populations. In addition, a systemic incentive plan will be developed to engage family members, NGOs, volunteers and other stakeholders in the local community to carry out activities that complement public services. Informal carers play a crucial role in making it possible for people with dementia to remain in their home environments for as long as possible. Systemic education, training and adequate social support for these carers can also help to reduce the burden on professional staff. Families, in particular, bear a significant responsibility in providing care, and without adequate support from the state, they risk becoming overwhelmed and possibly needing medical care themselves.

[34] A community nursing service (or a nurse) that specialises in dementia requires additional training in the speciality. Ideally, specialist dementia nurses should have at least two years practice experience in dementia care and a registered mental health nursing qualification. Most of them should also have qualifications equivalent to a Bachelor's degree and would be expected to specialise further towards a Masters degree, as the nature of their work cuts across many areas of medicine. The good care Group, Recognising The Role Of The Specialist Dementia Nurse In The Community, https://www.thegoodcaregroup.com/news/recognising-role-specialist-dementia-nurse-community/

6 EDUCATION AND RESEARCH

6.1 Education

Awareness-raising and education are key to the Strategy's successful implementation. The essential structural and content components of education include the following:

- Education must target different segments of society, including:
  - the general public,
  - professional groups likely to come into contact with people with dementia (such as the police, fire service, paramedics, judges, lawyers, architects, local community workers such as bus drivers, taxi drivers, librarians, finance officers, retail and catering staff and so forth),
  - family members, i.e. informal carers,
  - professionals within the dementia care pathway (healthcare, social care and long-term care professionals);
  - people in the early stages of dementia,
  - policy decision-makers, and
  - other stakeholders;
- Education should target all age groups in an appropriate format, both as part of the formal education curricula (from kindergartens to third age universities) and as informal education, tailored to specific needs and interests;
- Education should include knowledge about healthy lifestyles and ways to prevent or delay neurocognitive disorders; comprehensive treatment options, both pharmacological and non-pharmacological; communication, conflict management and recognition of all forms of violence, especially against women and other vulnerable groups; social and other psychological, economic, legal and other aspects of dementia as a bio-psycho-social phenomenon;
- Education and support should be designed to empower people with dementia and their family members to fully exercise their rights, as long as this does not compromise the health and/or rights of the person with dementia and others;
- Specific upskilling and training programmes should be developed for staff, with a focus on introducing new practices through interdisciplinary approaches, such as integrated and multidisciplinary treatment, cooperation protocols and new clinical pathways.
- Encourage the creation or development of disciplines, studies, specialisations, undergraduate and postgraduate programmes that improve the knowledge and treatment of people with dementia (geriatrics, psychogeriatrics, gerontology, social gerontology, specialist community nursing services, etc.);
- Forms of education must be based on modern pedagogical and technological methods;
- Responsibility for the implementation of these tasks falls under the newly established National Dementia Centre.

6.2 Research

Despite improvements over the past decade, research into dementia in Slovenia remains inconsistent. With this Strategy, we are committed to actively promoting research related to the treatment of people with dementia.

- Given the lack of organisational coordination between universities, institutes, associations and research centres (e.g. Spain – Consortium of the Biomedical Research Network in Neurodegenerative Diseases (CIBERNED), France), the Strategy aims to foster research synergies by establishing a national coordinating body. This body will include multidisciplinary professionals and provide certified training on dementia through a dedicated dementia centre.
- Due to low investment in research in general, dementia research currently accounts for less than 1.5% of all health research outputs. This is despite the fact that dementia is the seventh leading cause of death worldwide. It should be noted that dementia research is particularly challenging, with slower progress, lower success rates and longer development phases, often due to the inclusion of older and polymorbid patients. To address this, increased funding for

dementia research is essential. Public and private funding plans should be developed in cooperation with the Ministry of Higher Education, Science and Innovation.

- We need to move beyond a purely biomedical approach to dementias and adopt a biopsychosocial model, as recommended by the WHO in its classification.
- It is essential to improve the balance between research contributions from different areas: basic and translational research, clinical trials, pharmacological and non-pharmacological approaches, health economics, new telemedicine and digital health technologies, sociological (legal and ethical) studies, epidemiology and public health research, as well as future scientific and technological advances, such as artificial intelligence, multi-omics and biomarkers.
- Currently, the insufficient share of epidemiological and public health research hinders more successful dementia policy planning.
- People with dementia, their families, associations and other target groups still lack information about research findings. Moreover, there is also a lack of information on how to contribute to and participate in clinical research or tissue donation programmes. It is important to encourage the involvement of people with dementia, their carers, families and society in research. Researchers should systematically and responsibly share knowledge and research findings with both the professional community and the general public.
- One of the major challenges in treating dementia is that by the time a diagnosis is made, the brain is irreparably damaged. It is therefore essential to focus on the following:
  - Research into biomarkers that allow early and pre-symptomatic diagnosis, thus increasing the window of opportunity for successful therapeutic strategy;
  - Research and development of new therapeutic strategies aimed at preventing or significantly slowing the progression of dementia symptoms;
  - Research and education on lifestyle as an option for the prevention/delay of dementia and their integration into primary and secondary programmes for the prevention of neurocognitive disorders.
- Research and deployment of innovative health and social technologies at universities and public-private partnerships is also crucial, as these technologies can play an important role in dementia prevention and risk reduction, early diagnosis, treatment, care and support. While encouraging these new approaches, it is important to put in place mechanisms to prevent exploitative commercialisation in this sector.
- A systematic and regular monitoring system and a core set of indicators on dementia diagnosis and its progression should be established to guide action, improve services and measure progress in implementing national dementia strategies. This will require significant changes in the systematic processes of collection, registration, integration and disaggregation to exchange medical and administrative data for each encounter a person with dementia has within the health and social care system. Examples of good practice, such as a national registry, are already known (UK, Sweden) and could be adapted and applied in Slovenia. To this end, resources should be made available for the recruitment of staff and the use of technical equipment, including a biobank.
- Improving the accuracy of final diagnosis coding is crucial for the proper selection of candidates for clinical trials, whether observational or interventional.
- In Slovenia, international cooperation is already taking place at the clinical, basic and international levels, as well as through cooperation with patient associations. Participation in initiatives such as the EU Joint Programme on Neurodegenerative Disease Research (JPND) is promising, but efforts to improve and strengthen international cooperation in dementia research at all levels and in all areas need to be further encouraged and strengthened.

7 MANAGING DEMENTIA DURING EPIDEMICS AND OTHER CRISES

People with dementia are a particularly vulnerable group because of their impaired cognitive abilities, which include difficulties with language, orientation, thinking and judgment. First responders often encounter these persons while searching for wandering patients. In emergencies such as natural disasters, fires, storms, power outages, earthquakes, or epidemics, people with dementia need special assistance, because they are typically unable to accurately assess danger, seek help independently, or follow emergency instructions. Most people with dementia live at home, either alone or with extended family, and receive assistance from family members and neighbours. However, as the number of people with dementia continues to grow, it is imperative that local communities are prepared to respond effectively to rescue them in emergencies.

The strategy for the rescue of the elderly and infirm in the field should include an emergency plan specifically tailored to the care and rescue of people with dementia. This plan must ensure:

- effective access to critical information about patients (location of residence, family contact information);
- sources of assistance (civil protection, fire brigade, Red Cross, social service and community nursing service),
- rescue routes for people with dementia, especially those living alone at home.

Dementia awareness, including an understanding of the behaviour of people with dementia and the specific emergency measures required when assisting them, should be included as a core competency in the training of emergency responders.

During the COVID-19 pandemic and similar epidemics, we must prioritise the protection of people with dementia through vaccination, as their cognitive decline makes it difficult for them to understand instructions to prevent infection and to avoid uncontrolled physical contact.

Because of these impairments, they may struggle to follow instructions or guidelines intended for the general population. A specific plan of measures to manage dementia during epidemics and other crises will be developed in accordance with the action plan. In addition, existing plans should be reviewed and measures supplemented to ensure the protection of the human rights of persons with dementia during such emergencies.

8 MANAGEMENT, COORDINATION AND EVALUATION OF STRATEGY IMPLEMENTATION AND STARTING POINTS FOR THE ACTION PLAN

The Strategy systemically addresses the challenges associated with dementia and complements existing national strategies (particularly in the health and social care sectors) that influence the management of dementia and the creation of a dementia friendly environment. The Ministry of Health is responsible for the effective, efficient and high-quality management, coordination and evaluation of the Strategy, working in cooperation with:

- the Ministry of a Solidarity-Based Future, the Ministry of Labour, Family, Social Affairs and Equal Opportunities, the Ministry of Justice and other ministries;
- The National Institute of Public Health;
- The Social Protection Institute of the Republic of Slovenia;
- local government representatives.

In addition to improving the (co-)operation among existing structures, new ones will be established for the effective management and coordination of the national dementia strategy. A dedicated Mental Health and Dementia Division has been established within the Ministry of Health.

A centre for dementia or cognitive decline will be established as a central national institution with primary responsibility for training and education of staff involved in dementia care, coordination of professional development and research activities, and professional implementation of the national strategy, including evaluation of individual measures. Drawing on data and research, the centre will provide expert assessments and recommendations for policy makers to improve the management of dementia. The centre will be supported by a network of regional memory centres operating across health regions to ensure that residents have access to appropriate diagnosis and treatment close to home. The National Dementia Centre and memory centres will work with other services, particularly in neurology, psychiatry, family medicine, psychology, psychotherapy and social care. The aim is not to replace existing activities but to create additional structures and activities for people with dementia and their family members that complement the existing structures of providers.

The Strategy, through its Action Plan, outlines specific actions, designates responsible authorities and defines implementers of the actions, sets timelines, identifies financial sources, and establishes indicators for regular annual evaluation of its implementation. In addition, an external evaluation of the Strategy will take place at least every five years. Action plans will cover periods of two to five years and will be annexed to the Strategy. The first action plan will be developed for a period of two years and will be adopted after the adoption of the Strategy.

9 GLOSSARY OF TERMS

If a term is not defined within this Chapter, please refer to the glossary in the Global Dementia Observatory Reference Guide to clarify its use in this Strategy.[35]

Health promotion centre:
Health promotion centres are independent organisational units within community health centres. They run health promotion programmes (group workshops and one-to-one counselling aimed at fostering long-term changes in lifestyle habits for improved well-being and health). They also lead activities to promote health and reduce health inequalities within the local community.

Adult mental health centre:
Adult mental health centres are established within community health centres to provide mental health services for adults, covering the needs of between 50,000 and 70,000 adults over the age of 19. Their services are designed to ensure equal access to the entire population of the area they cover. The centres work in partnership with locally-based services to provide integrated interdisciplinary interventions. Services include home-based and outpatient treatment, covering triage and counselling.

Dementia-friendly environment:
A dementia-friendly environment involves adapting both the physical and social environment to better accommodate people with dementia. This ensures easier access to everyday goods and essential services, while promoting communities that are more inclusive, accessible and welcoming to people with dementia and their family members.

Destigmatisation:
A process aimed at reducing the stigma attached to certain health conditions or diseases.

Long-term care:
Long-term care comprises a series of services that are needed by people with diminished physical and cognitive abilities, who, as a result, are dependent over a longer period of time on assistance in performing basic or every-day support tasks. This will be an increasing challenge in the future as the population ages, and trends indicate that this population will face disabilities and will therefore need support in basic daily activities.

Dementia:
Dementia is a progressve and emerging medical condition characterised by impairments in memory, cognition, orientation, recognition, understanding, speech, judgment, behaviour, sensation and emotion. These impairments limit the affected person's ability to engage in day-to-day activities and eventually result in the need for assistance from others.

Integrated services:
Integrated services are coordinated and collaborative approaches to delivering health, social, or public services that bring together multiple providers, sectors, or disciplines to ensure that individuals receive comprehensive, seamless, and person-centered care or support.

Frailty:
Frailty is a common geriatric syndrome characterised by a dynamic decline in physical, psychological, and/or social functioning. It is a major public health concern because of its clinical and social implications, but it is also potentially reversible because of its dynamic nature. Early intervention can improve a patient's quality of life and mitigate negative health outcomes, thereby supporting healthy ageing.

Multidisciplinary approach:
A multidisciplinary approach involves the cooperation of different academic disciplines or professional specialisations to address a particular case or problem.

Non-governmental organisation:
A non-governmental organisation is an organisation that has been granted the status of a public interest association by the competent ministry pursuant to the Societies Act (Official Gazette of the Republic of Slovenia [Uradni list RS], Nos 64/11 - official consolidated version and 21/18 - ZNOrg) or the status of

[35] The Global Dementia Observatory Reference Guide. Geneva, Switzerland World Health Organization, 2018, https://apps.who.int/iris/handle/10665/272669 (access 26 October 2022).

a humanitarian organisation pursuant to the Humanitarian Agencies Act (Official Gazette of the Republic of Slovenia [*Uradni list RS*], Nos 98/03 and 61/06 - ZDru-1).

Basic palliative care:

Basic palliative care focuses on the holistic management of a patient throughout the course of their illness, aiming to alleviate physical symptoms while also addressing the patient's mental and spiritual well-being. Throughout the patient's treatment, family members are actively involved in the care, if they agree and wish to participate. The basic palliative support is provided by the chosen personal doctor and a community nurse or, in care homes, the care home's doctor and multidisciplinary team. In-home nursing and social support are delivered through the home help system under the Long-Term Care Act. If needed, a psychiatrist can be included in the medical treatment at home, with home visits provided by community-based psychiatry or a mobile team from the adult mental health centre. Other specialists can be brought in to supplement basic palliative care as needed.

Dementia literacy:

Dementia literacy is a set of cognitive and interpersonal skills (or cognitive and social skills) that enable people to understand how to acquire and maintain health-promoting factors, recognise the characteristics of dementia treatments, reduce the stigma associated with dementia, and seek help effectively (knowing when and where to seek help). It also involves developing the skills necessary for personal care, both mental and physical, and improving the ability to care of oneself.

Stigma:

Stigma is the negative characterisation (labelling) of an individual because of characteristics or a condition, such as a disease, that sets them apart from others. When a person is labelled/stigmatised because of a condition, the people around them no longer see them as an individual, but as a member of a group commonly that is usually stereotyped. Stigma includes (i) stereotypes (positive or negative social opinions on a certain group of people), (ii) prejudice (mental and emotional responses to stereotypes) and (iii) discrimination (behavioural responses to prejudice). There are several types of discrimination, the most common being stigmatisation by family, professional services and friends, and in the workplace. Self-stigma is an internalised stigma that manifests itself in a loss of self-esteem and effectiveness.

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