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A trumpet is positioned diagonally across the upper half of the image, pointing towards the bottom left. Below it, a large, detailed rose is shown in profile, facing left. The background is a solid yellow color, with a blue abstract shape in the top right corner and a blue and white abstract shape in the bottom right corner.

25 years living with dementia

Praha 2022

25 years living with dementia

Martina Mátlová

25 years living with dementia

Exhibition catalogue. Kampa, November 6–28, 2022

Martina Mátlová

English translation: Martina Miššíková

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Česká alzheimerská společnost, o.p.s.
2022



VIATRIS MEDIALOGUE

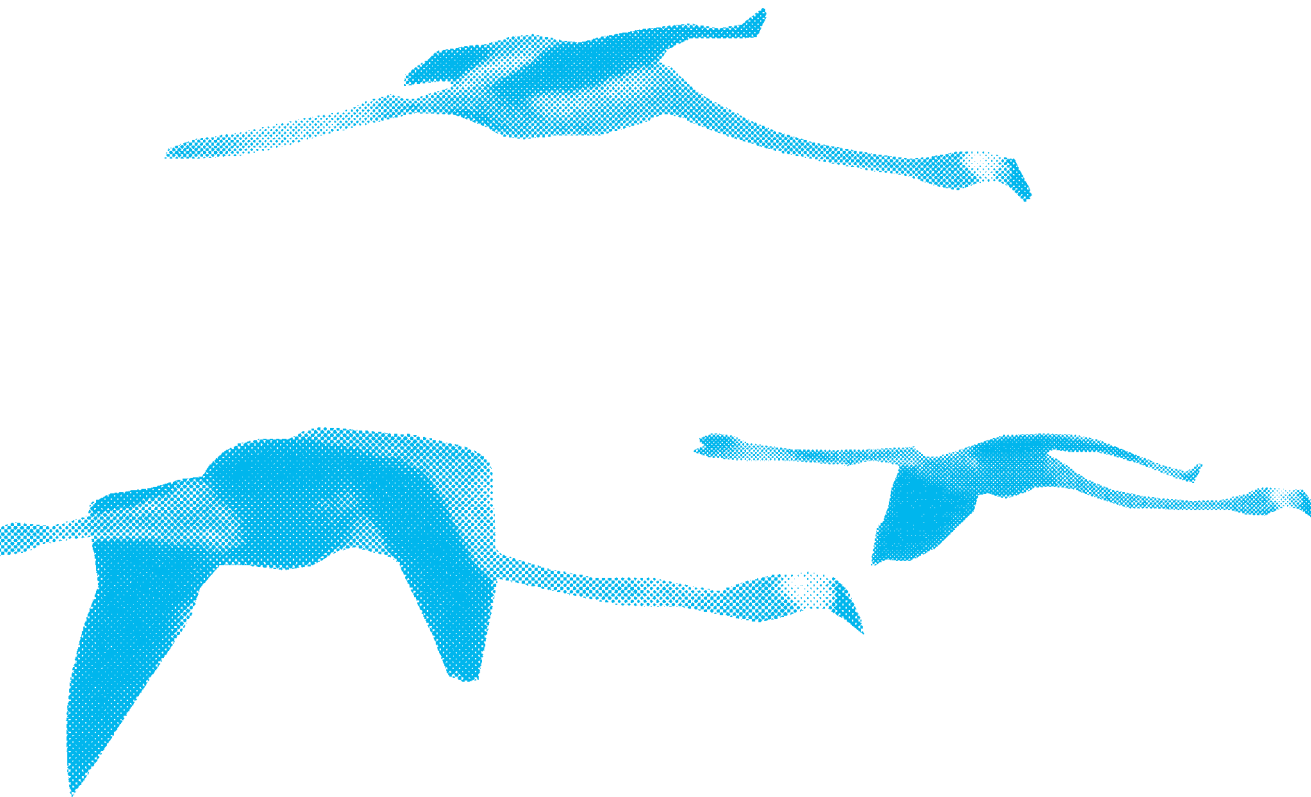


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25 years living with dementia

The Czech Alzheimer Society (CAS) has been helping people with dementia and those who care for them since 1997. Since its establishment, the mission of CAS has been to draw attention to issues related to dementia, pointing out that life for people with dementia in the Czech Republic is rather difficult and that with the expected increase in the number of people with dementia, the situation will turn into a massive problem not only for people with dementia and their families but also for society as a whole. Do we still have some time to prepare?



Does Alzheimer disease equal dementia?

In recent years, Alzheimer's disease has become almost synonymous with dementia. (Incidentally, the Czech Alzheimer Society also does not have dementia in its name, although it offers its services to people with all types of dementia.) The disease named after Alois Alzheimer is, however, only one of the causes of dementia, albeit a very significant one, since very likely two out of three cases of dementia are due to Alzheimer's. The second most common type of dementia is vascular dementia, caused by problems with blood vessels. Other types of dementia include Lewy Body dementia (LBD) or Pick's disease (or frontotemporal dementia FTD). Dementia is also relatively common in people suffering from Parkinson's disease or those with Down's syndrome; dementia is a serious consequence of excessive drinking; and it has a quick onset in the infectious Creutzfeldt-Jakob disease. Often two types of dementia occur at the same time – typically Alzheimer's disease and vascular problems – in which case we speak of mixed dementia. Sclerosis as well as 'old-age dementia' are outdated and incorrect terms, despite the fact that the latter is used in Czech legislation on social services.

It is important to note that some of the symptoms typical of dementia may be the result of another disease or an acute condition and are therefore reversible. This is the case, for example, with symptoms of depression or dehydration, especially in older people.

Types of dementia

Alzheimer's disease 62 %

vascular dementia 17 %

mixed dementia 10 %

Parkinson's disease 5 %

other rarer causes 4 %

other neurodegenerative brain diseases 2 %



Alzheimer disease or Fischer disease?

Until recently, Alois Alzheimer, the German physician who famously described the case of Augusta D. in 1907, was considered the undisputable 'father' of Alzheimer's disease. At the same time, however, similar research was conducted simultaneously at the Prague School of Neuropathology, headed by Arnold Pick (yes, frontotemporal dementia or Pick disease is named after him). Oskar Fischer was part of the research team and, like dr. Alzheimer, he described the so-called senile plaques. Although his research work was, at least in today's terms, superior to Alois Alzheimer's, it has fallen almost into oblivion. The studies of Oskar Fischer were only discovered in 2007 in connection with the centenary of the first publicized description of Alzheimer's disease. The discovery was made by Michel Goedert of the Laboratory of Molecular Biology at the University of Cambridge whose findings were published in peer-reviewed journals. This led to recognition for Oskar Fischer and a science award was named in his honour. Oskar Fischer's life recalls the tragic fate of many European Jews.



Oskar Fischer
12. dubna 1876, Slaný
28. února 1942, Terezín

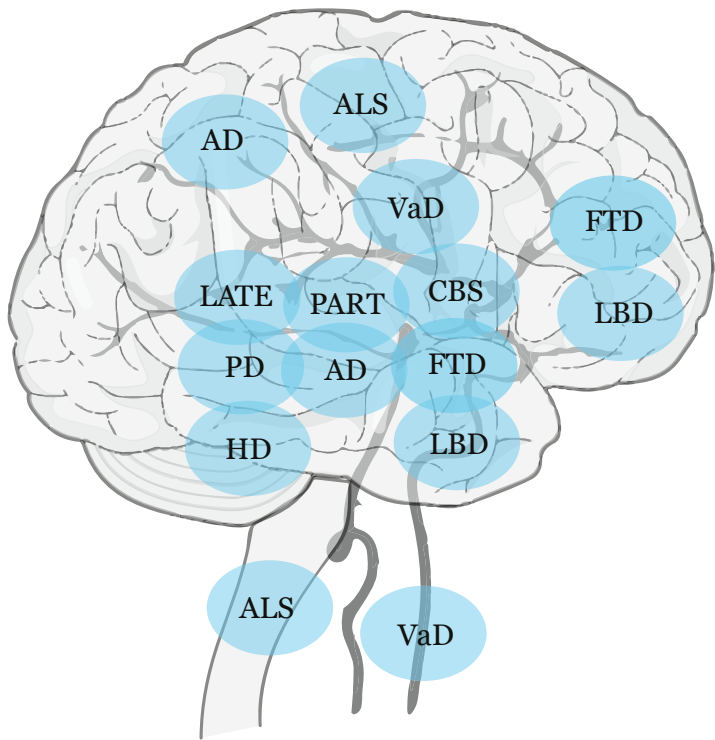


Arnold Pick
20. července 1851, Velké Meziříčí
4. dubna 1924, Praha

Do we know what is happening in the brain?

The exact mechanism of action in Alzheimer's disease (and this is perhaps even more true for other causes of dementia) remains unclear despite extensive research and despite the fact that we have learned a great deal about Alzheimer's disease. We know for a fact that two proteins and their pathological deposition – amyloid beta and tau – play a significant role, as does neurodegeneration. Understanding what is actually happening in the brain and why, is absolutely crucial to finding an effective cure.

Schematic diagram summarising vascular abnormalities and proteinopathies involved in cognitive decline and dementia



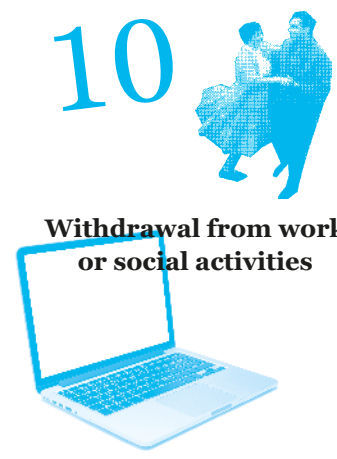
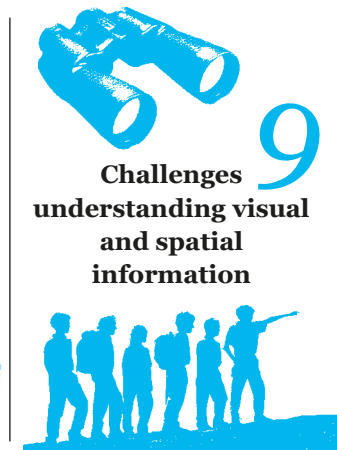
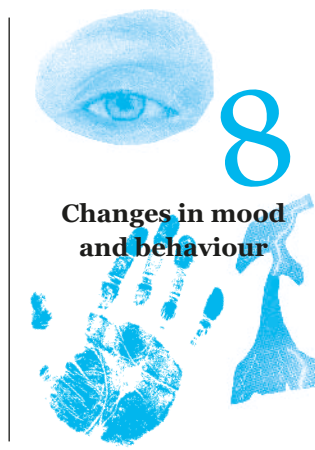
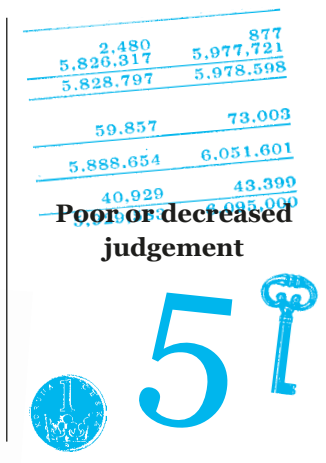
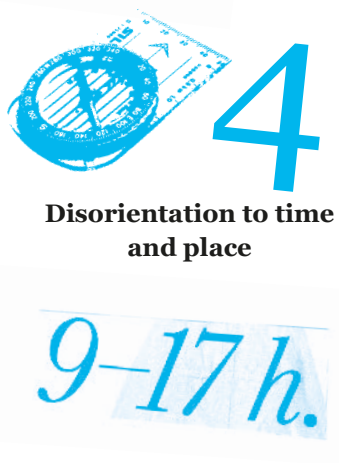
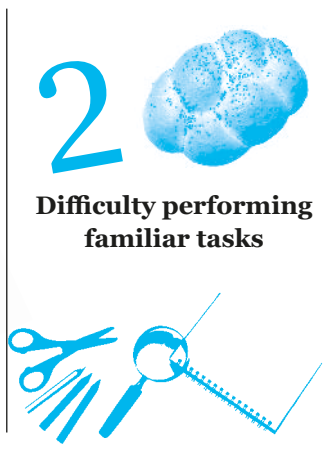
Source: World Alzheimer Report 2021. Journey through the diagnosis of dementia. str. 162, Alzheimer's Disease International. 2021.

Alzheimer's disease (AD) Location: temporoparietal cortex Predominant Proteinopathy: A β plaques and tau tangles (3R:4R)	Vascular dementia (VaD) Location: blood vessels Predominant Proteinopathy: aggregated amyloid, aggregated, or granular osmiophilic material (GOM), or atherosclerosis	Corticobasal syndrome (CBS) Location: sensory and motor cortices, basal ganglia Predominant Proteinopathy: A β plaques and tau tangles (3R:4R) and tau tangles (4R)
Limbic-predominant age-related TDP-43 (LATE) Location: Limbic Predominant Proteinopathy: TDP-43	Primary age-related tauopathy (PART) Location: Limbic Predominant Proteinopathy: Tau tangles (3R:4R)	Frontotemporal Dementia (FTD) spectrum Location: frontotemporal cortex Predominant Proteinopathy: tau tangles (3R or 4R), TDP43, FUS and pick bodies
Parkinson's disease (PD) Location: midbrain Predominant Proteinopathy: Lewy bodies	Huntington's disease (HD) Location: basal ganglia Predominant Proteinopathy: poliQ inclusions	Lewy Body dementia (LBD) Location: frontotemporal cortex Predominant Proteinopathy: Lewy bodies
Amyotrophic lateral sclerosis (ALS) Location: Motor cortex, brainstem, spinal cord Predominant Proteinopathy: TDP-43, FUS		

What signals should you pay attention to?

If you observe the symptoms mentioned above, please visit your GP. For people aged 65 to 80, a memory test is part of a regular preventive check-up. If for any reason you can't find help from your GP, get your memory tested as part of the Memory Days project.

10 warning symptoms



Can dementia be cured?

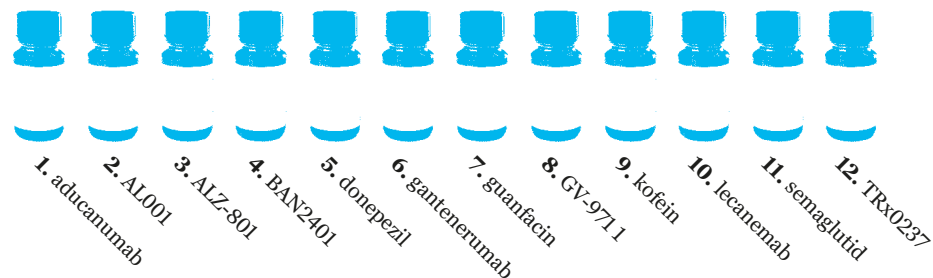
Neither dementia nor its most common cause, Alzheimer's disease, can yet be cured. Cognitive agents (mainly acetylcholinesterase inhibitors) are used to treat Alzheimer's disease and have the potential to improve the quality of life of patients. Cognitive agents halt the progression of the disease to some extent, but they cannot reverse the decay once the disease has progressed. This is why it is so important to start treatment at a time when the brain has not yet been irreversibly damaged.

Thanks to efforts by the Czech Alzheimer Society, acetylcholinesterase inhibitors were included among the drugs covered by public health insurance in 2002. Since then, we have been waiting for a breakthrough in terms of new drug treatment. There are currently 21 ongoing clinical trials in Phase III, according to Alzheimer Europe and its Clinical Trials Watch project. Of these, six are being carried out also in the Czech Republic.

Given the current state of knowledge in the field of treatment, non-pharmacological methods are of great importance. That is approaches not using drugs to improve the quality of life of patients. Examples include validation, reminiscence therapy, basal stimulation, dance therapy or Namaste care.

At the begining of 2022, CAS published 'Non-Pharmacological Ways to a Better Life with Dementia', a book describing the most common non-pharmacological methods that benefit people with dementia. We also cover some of the non-pharmacological methods in our courses for lay and professional carers.

Effective substances undergoing testing in phase III of clinical trials



Who is dementia most likely to affect?

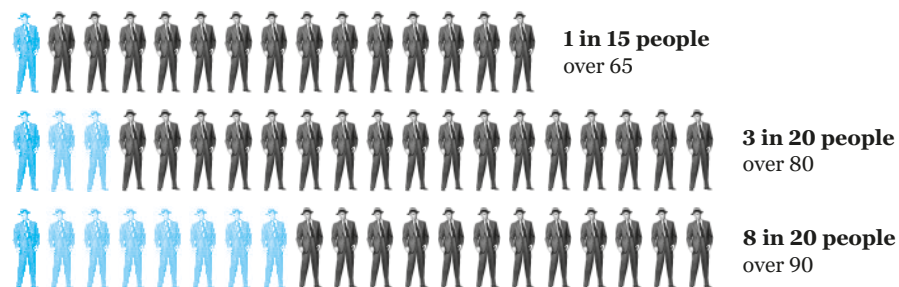
Women are much more likely to suffer from dementia than men. According to Alzheimer Europe prevalence studies, in 2001 there were 50 597 men living with dementia in the Czech Republic, while the number of women was more than double at 110 075. Women are also much more likely to become caregivers – either informally at home (three in four people who contacted us in 2021 were women) or as their regular job.

Although dementia is not a natural part of ageing and is always the result of an illness, it can be said that the older a person gets, the higher the risk of developing some type of dementia. According to Alzheimer Europe, in the Czech Republic, 7% of people aged over 65 live with dementia, compared with 15% of people over 80 and as much as 41% of people aged 90 and over.

Gender and dementia in CZ (2021)



Age and dementia in CZ (2021)



Is this a major problem?

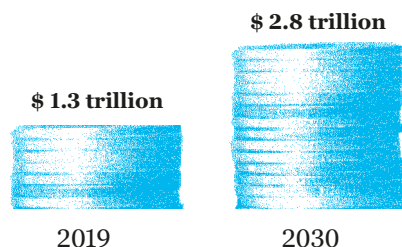
Every year, there are up to 10 million new cases of dementia worldwide. The World Health Organization (WHO) estimates that there is a new case of dementia every three seconds. According to these projections, in 2019 there were 55 million people with dementia living worldwide and the number will almost triple by 2050. According to international organisations, much attention needs to be paid to societies in low-income areas of the world where the increase in people with dementia is likely to be steepest. Dementia ranks among the ten most common causes of death.

Calculating all the costs associated with dementia is not easy, yet the WHO estimates that in 2019 these costs have reached USD 1.3 trillion. This amounts to the GDP of the 12th–14th largest economies in the world (Brazil, Australia or Spain). The WHO projects that the global cost of dementia will have more than doubled by 2030. To put this in perspective, the GDP of the world's fifth largest economy, the United Kingdom, was at USD 2.64 trillion in 2020.

Estimated number of people with dementia worldwide



Dementia related costs worldwide



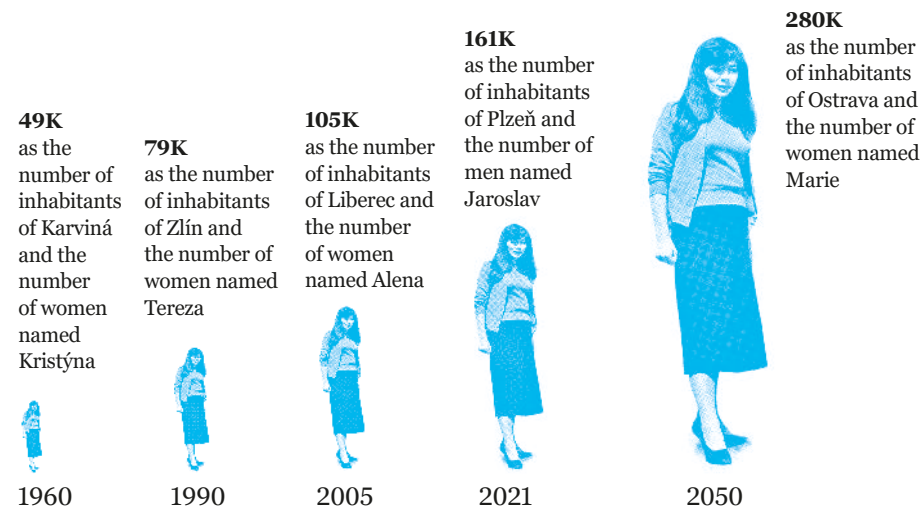
Source: WHO, Fakta o demenci.

Is dementia an issue in the Czech Republic?

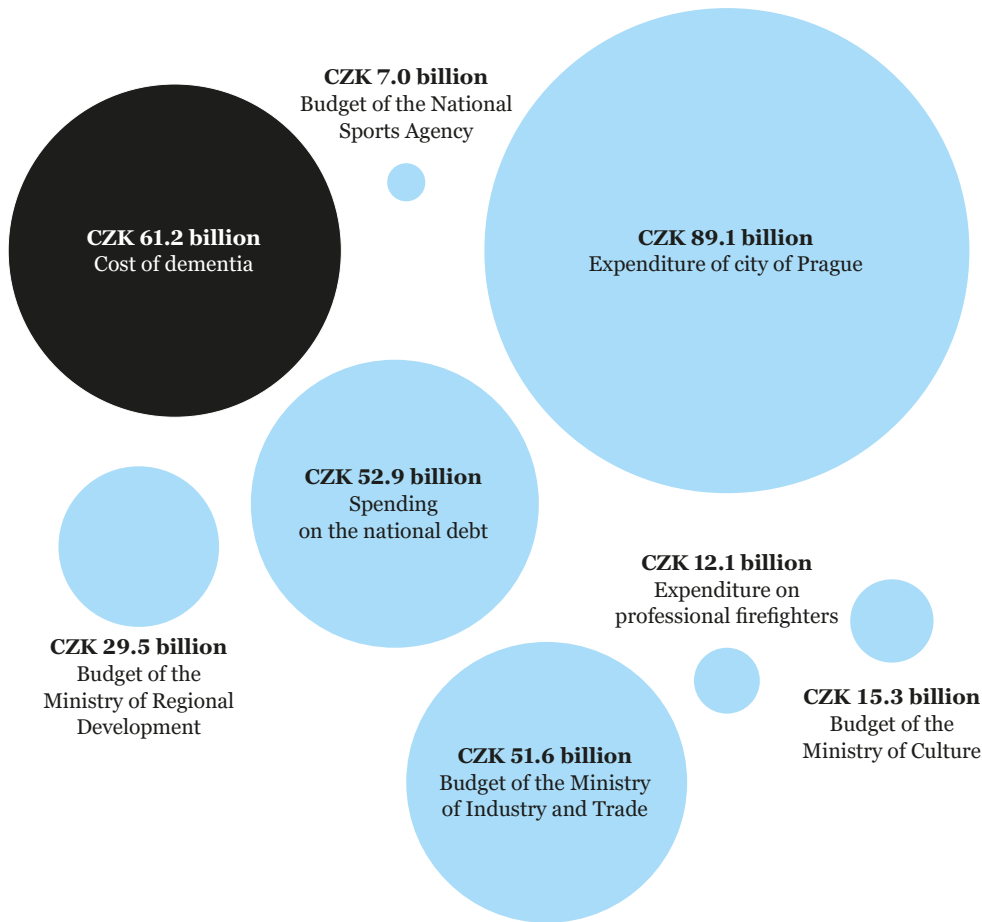
To find the best solution, it is essential to have the problem perfectly described. However, we are only left guessing when it comes to the number of people with dementia in the Czech Republic. We rely on a large prevalence study by Alzheimer Europe which estimates the proportion of people with dementia in each age group. Thanks to this study and based on data from the Czech Statistical Office, we assume that there will be almost 161 000 people with dementia in the Czech Republic at the end of 2021. The number of people with dementia will continue to increase in the Czech Republic, similar to the developments in other European countries. By 2050, the number of people with dementia is likely to be almost double the current number. It all depends, however, on how the age structure is going to develop – using the same calculation methods in combination with the high variant of the official age structure projection, we get a result higher by 50 000 cases.

To estimate the cost of dementia in the Czech Republic, we rely on a study by Alzheimer's Disease International. This study assumes that the cost of dementia in the developed countries of the world is about 1% of their GDP. According to a sober estimate, the cost of dementia in the Czech Republic could thus reach CZK 61.2 billion in 2021. This is roughly the same as the budgets of the Ministry of Culture, the National Sports Agency, the Ministry of Regional Development and the expenditure on professional firefighters combined.

Estimated development of number of people with dementia in CZ



Comparison of dementia related costs with selected items from thenational budget (2021)



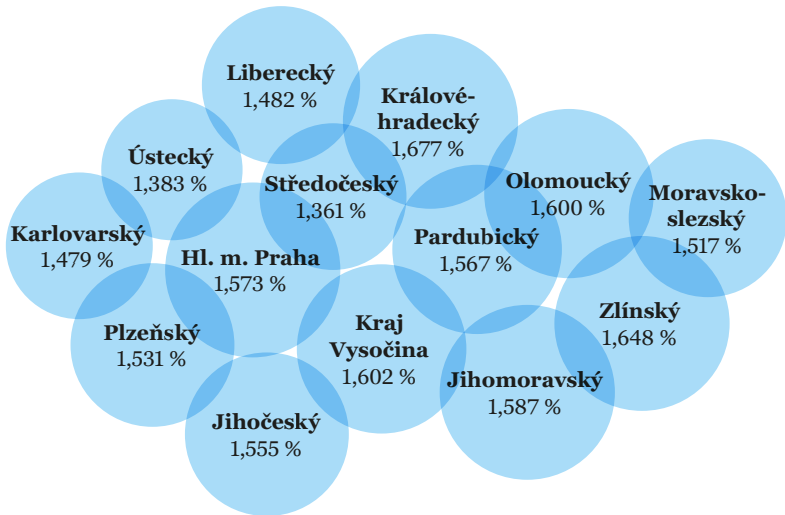
Source: Dementia in Europe. Yearbook 2019. Estimating the prevalence of dementia in Europe. Alzheimer Europe, 2020 a vlastní výpočty

Which region has the most people living with dementia?

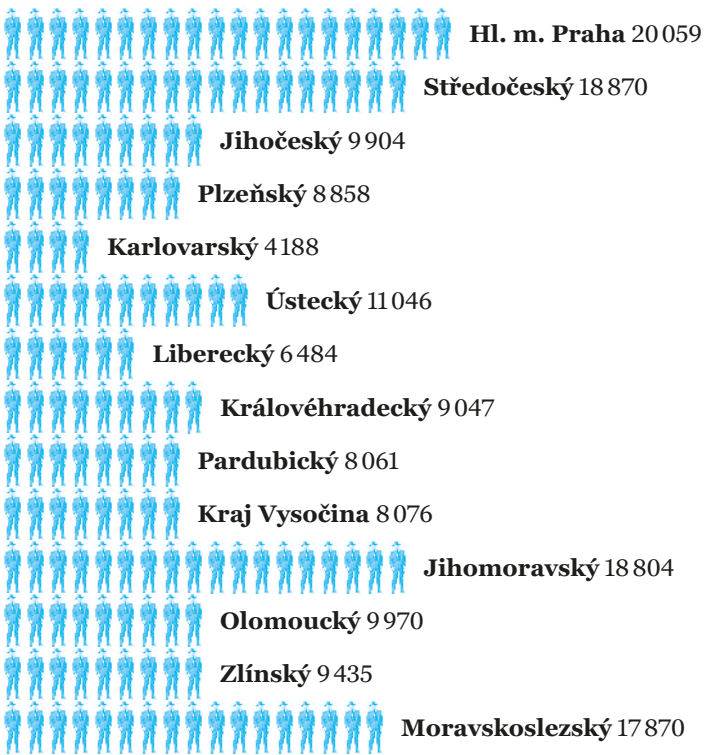
To get a reliable estimate of the number of people with dementia, you need to consider the demographic structure and development, as well as the total population of a region. Prague is the region with the highest number of people with dementia, followed by the populous regions of Central Bohemia, South Moravia and Moravia-Silesia. The number of people with dementia in these regions is up to 20,000, about the population of an average-sized district town. (However, the age structure of the population in each region has been greatly influenced by covid. For example, in the Karlovy Vary region, we estimate that the number of people with dementia in 2021 will have fallen for the first time compared to the previous year!)

The proportion of people with dementia in each region is an interesting figure to look at. The data, again, is based on the Alzheimer Europe prevalence study, so the differences between regions are only due to the current age structure of the region's population. The highest proportion of people with dementia live in the 'oldest regions' – Prague, followed by Zlín, Hradec Králové, Olomouc and Vysočina.

Proportion of people living with dementia by region (2021)



Number of people living with dementia by region (2021)



CAS has offices called ‘contact points’ in all regions. They act as independent organisations, cooperating closely with CAS, and offering a wide range of services for people with dementia, including counselling. People working for CAS and its contact points are open and accessible, providing high quality care and always willing to go the extra mile for people with dementia.

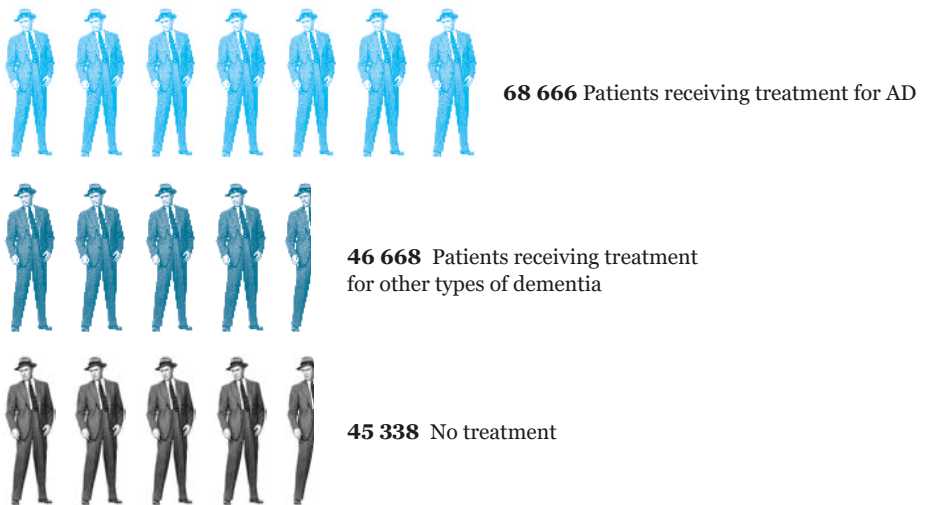
Source: Dementia in Europe. Yearbook 2019. Estimating the prevalence of dementia in Europe. Alzheimer Europe, 2020 a vlastní výpočty

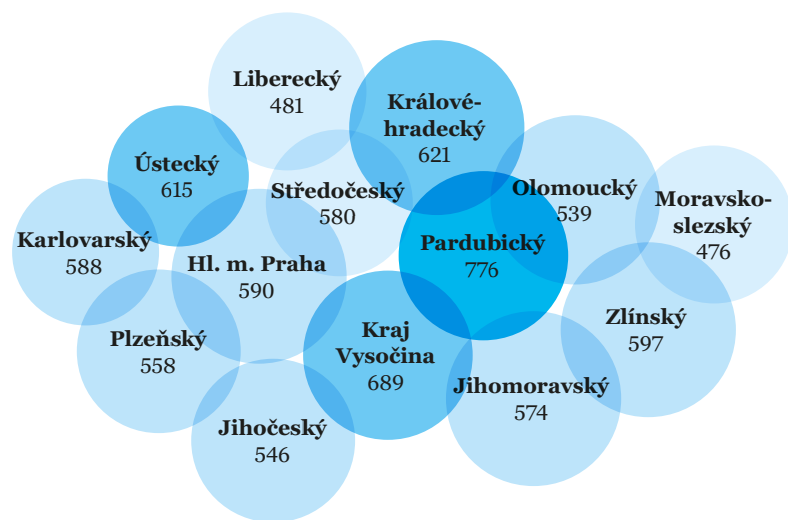
How many people with dementia are treated in CZ?

For people with dementia to have a good quality of life, the most important thing is a timely and correct diagnosis, followed by appropriate treatment. It is therefore worth monitoring the proportion of people with dementia receiving treatment. According to open data of Ministry of Health, most likely 70% of people with dementia have received some form of therapy in recent years. This seems to be a rather good result, as globally the ratio is reversed, according to data from the ADI. However, it still means that about 50 000 people in the Czech Republic have no treatment at all. The timing of the diagnosis is also of essence. The sooner the client is diagnosed after the first symptoms appear, the better. We do not yet have enough data to assess when and how people get diagnosed.

A detailed analysis by the Institute of Health Information Services in 2018 has revealed that there are vast differences in the approach to diagnosis throughout the Czech Republic, as shown by data on the number of people treated with Alzheimer’s disease in each region. When adjusting for differences due to population size and age structure, we see that residents of the Pardubice region are more than 1.5 times more likely to be diagnosed with Alzheimer’s disease than people from the Moravian-Silesian Region. This difference signals significant inequality in care.

People with/without treatment for dementia (2021)





What health and social services are available?

Dementia is an example of an issue encompassing both health and social aspects. The response requires a close cooperation between health and social services. The health condition of people with dementia is gradually deteriorating to such an extent that, for example, it is not possible to provide quality care in residential social services without medical staff.

People with dementia need the whole spectrum of social services: counselling, mobile social services (individual assistance, nursing care or mobile respite services), day care centres and residential social services, such as homes for the elderly and homes with special services. Old people's homes are not, legally speaking, intended for people with dementia, yet a large percentage of people with some form of dementia most probably live there. According to an earlier survey, this figure may be as high as 70%. There are approximately 22 000 beds in residential care homes, which covers only as little as 13% of the total number of people with dementia. However, the availability of beds varies between regions – the Ústí nad Labem region has 3.5 times the resources compared to Prague. In the USA, for example, 30–40 % of people with dementia live in specialised homes. Residential respite services, which have the potential to significantly improve the lives of people with dementia and their families, also have insufficient capacities; for example, in Prague, only 175 beds are available for people with dementia.

Another significant issues is that dying people with dementia should receive palliative care. Yet in 2017, the latest year for which we have data, more than 12 000 people died with dementia.

The number of people with dementia and residential services



The capacity of homes with special services in the Czech Republic (2021)



The capacity of homes with special services in the Czech Republic (2021)



The capacity of nursing homes in the USA (2018)

Source: The role of care homes in end of life care. Briefing 1 - Care home bed provision and potential end of life care need in people aged 75 or older in England. Public Health England. 2017.
Jett L. Nursing Homes with Dementia Special Care Units Provide Better Quality of Care. Harvard Medical School. 2018. Statistická ročenka z oblasti práce a sociálních věcí 2021. MPSV. 2022.

Can you prevent dementia?

According to recent studies, it seems that healthy lifestyle can have a positive impact on Alzheimer’s disease. A person’s lifestyle is very likely going to influence whether they develop dementia or not but also how the condition is going to progress. The good news is that if we are mindful of our health and act preemptively against ‘civilisation diseases’, we are most likely ‘fighting’ the onset of dementia, too.

You can find memory and other cognitive training products for people with developing dementia on our website. Most health insurance companies offer an allowance for their purchase.

1

Be physically active

2

Follow a healthy diet

3

Enjoy social activities

4

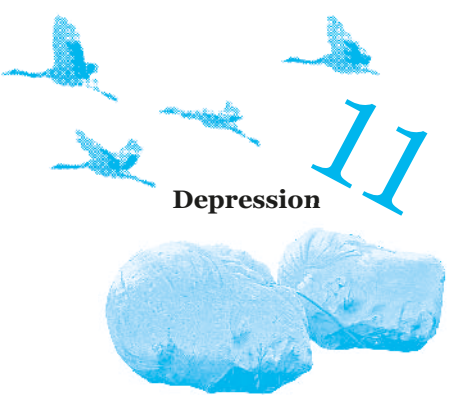
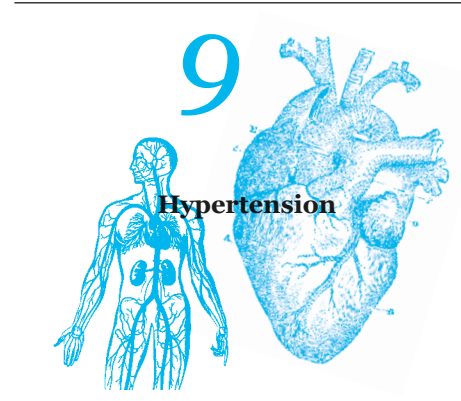
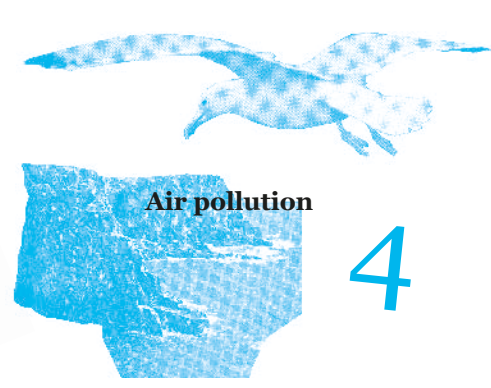
Challenge your brain

5

Look after your heart

Source: Alzheimer’s Disease International

What increases the risk of dementia?



Source: Livingston et al.: Dementia prevention, intervention, and care: 2020 report of the Lancet Commission; zpracováno podle ADL.

What is toughest about life with dementia?

What is the most difficult part of living with dementia? Difficult to answer because my wife can still take care of herself in terms of hygiene, find her way home. But you lose a human being, a partner, even though she is still here, she exists. There are two of us but I'm actually alone. The time when we should have enjoyed old age is over for both of us. The children have told me we have lost our mother, even though we have her. In other words, there are two levels to this. The working one, the worrying, the work, the caring, and the spiritual one, which is the loss of a person.

— *Mr P., currently caring for his wife*

There are many things that are difficult for a family carer, it is hard to say which is the most difficult because it changes throughout the course of the process of providing care. At the beginning: admitting that someone close to you has dementia, understanding the progression of the disease, grasping what is going to happen next. In the midst of it: deciding whether to care alone and to what extent, whether to work part-time or leave work altogether, finding support from family members, finding professional support. If you leave your job and provide care 24/7: social isolation, worse chances for a decent pension. If your loved one dies: unemployment benefit at 0.15% of the average wage, very difficult to find a job.

— *Mrs Ž., former family carer*

For me as a caregiver, the most difficult thing is to watch, feel and experience the hours, days and months with a person who is gradually losing his former full mental and physical abilities and strength. You simply find your husband, with whom I have shared several decades of a good life, gradually getting 'lost', escaping into 'another world'. This is a very, very stressful, I am not afraid to write, depressing feeling.

— *Mrs K., currently caring for her husband*

Is there something dementia can gift you with?

The experience of many nice moments while providing care, it is nice to take care of someone you are close to, to make them happy. Life isn't just about the big moments, life is made up of many seemingly insignificant moments, the nice thing about being a caregiver is when you can put your arms around your loved one, when you can stroke them, when they smile at you, when you can see that they are enjoying their meal. These may be little things but they are the essence of a nice relationship. I have gained confidence that I am doing the right thing and that I am doing it well.

— *Mrs Ž., former family carer*

Certainly the ability to rejoice even in the seemingly small things that one had not noticed before (or had paid only marginal attention to) under the 'overlay' of everyday life, perhaps the ability to better distinguish the truly essential, fundamental things from the useless, trivial things of no great significance, perhaps even the ability to take life as it is, with all respect, seriousness, but at the same time often with much needed detachment. Last but not least, thanks to respite – and subsequently palliative – care, I have met some excellent people whom I truly respect.

— *Mr P., former family caregiver*

Yes, a lot. I have realized, and continue to do so, the fragility and preciousness of every human life. I now have a deep respect for and bow deeply to anyone providing care for a person with dementia, be it an institution or an individual. I now realise how much patience, love and care they give every day to people with dementia, even when they themselves may not be well.

— *Mrs K., currently caring for her husband*

How can CAS help you?

Do you need basic information about dementia?

Check out our website www.alzheimer.cz or call us at 283 880 346.

Does your situation require a more in-depth conversation?

Call us on Mondays between 12.00 and 19.00 or make an appointment for a personal consultation at a time convenient for you.

Are you a caregiver for someone with dementia and need a few hours of rest a week?

Take advantage of our respite care (service available in Prague only).

Are you perhaps forgetful and afraid to go to the doctor?

Make an appointment for a memory screening as part of the Memory Days project.

Would you like to practice your memory and other cognitive functions?

Feel free to explore our portfolio of cognition training aids.

Do you provide care for someone with dementia and have no one to share your experiences and feelings with?

Visit our Tea at Five support group.

Are you looking for literature on the topic?

Download one of our brochures.

No time to read?

Watch our short videos covering 20 dementia related topics.

Are you interested in dementia and would like to enhance your education?

Browse our offer of accredited courses or book a bespoke course.

Do you provide high quality services for people with dementia?

Consider the Dragonfly® certification process.

Are you living with dementia and would you like to meet people sharing the same fate?

Join our Memory and Soul Walks support group.

Are you interested in our services but Prague is too far away for you?

Explore our contact points and the assistance they offer.

Milestones in the history of Czech Alzheimer Society (CAS)

- 1996** Meeting with Noreen Siba from Alzheimer's Disease International in the Gerontology Centre, Prague 8
- 1997** The Ministry of the Interior of the Czech Republic registers CAS as a civil association
- 2000** 13 contact points of CAS
- 2002** Aricept covered by public health insurance
- 2003** Public database of services for people with dementia
- 2008** P-PA-IA strategy as starting point for the Dragonfly® Certification, first people tested in the project 'Memory Days'
- 2010** First self-help support group for people with dementia called 'Memory and Soul Walks'
- 2012** The project of Gerontological and Organizational Supervision won the award of the Foundation Médéric Alzheimer
- 2014** Transformation of the legal body is completed Studio Najbrt created the new logo and visual style of CAS
- 2016** Iva Holmerová became the Chairwoman of Alzheimer Europe Workbooks for memory and other cognitive functions training activities were named the most beautiful book of 2015
- 2018** Twenty questions about dementia
Seven colleagues from the respite care service received awards for community service from the Mayor of Prague 8
- 2020** The Makropulos Award by the Ministry of Health for the project 'Memory Days'
Czech TV Award for a video promoting Twenty Questions about Dementia

How to support people with dementia and their families

Do you resonate with what we do? Do you want to support our work to improve the lives of people with dementia and their families?

Send us a DMS

Phone number: 87 777

DMS PROTIDEMENCI 30 or
DMS PROTIDEMENCI 60 or
DMS PROTIDEMENCI 90

The price of DMS is 30, 60 or 90 CZK. Czech Alzheimer Society will receive 29, 59 or 89 CZK. More information can be found on the website www.darcovskasms.cz

You can also support us by donating to the special account 20250277/0100.
Thank you



Exhibition organiser Česká alzheimerská společnost, o.p.s.

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For ten years, the Alzheimer's Foundation has been supporting experts involved in the research, diagnosis, treatment and care of patients with Alzheimer's disease and other neurodegenerative diseases. It regularly awards scholarships for young scientists and physicians, and a special grant for researchers who are mothers at the same time, it organises competitions for best scientific publications and active participation at conferences and participates in the Alzheimer Café project. www.alzheimernf.cz