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ŽIVOT S DEMENCÍ

# Understanding Dementia:

## A complex guide for the general public

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Charita Ostrava

OSTRAVSKÁ UNIVERZITA LÉKAŘSKÁ FAKULTA

alzheimer home

Aldring og helse Nasjonal kompetansetjeneste

**The brochure „Understanding Dementia: A Complex Guide“ aims to shed light on dementia and provide valuable knowledge, practical tips and information for anyone needing help in understanding the complexity of this disease.**

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## Part 1:

# What is dementia?

The word "dementia" is a general term encompassing a group of symptoms that affect thinking, mood, emotions and behaviour to such a degree that it affects the individual's capability to carry out basic everyday activities. Dementia usually gradually progresses over time, and the affected individual finds independent performance of everyday activities increasingly difficult. Dementia is not a part of the natural ageing process, which makes the term "geriatric" or "senile dementia" misleading. Dementia results from pathological processes or other serious causes (such as an injury or poisoning) affecting the human brain. Such processes then lead to the formation of different types of dementia. Alzheimer's disease is the most common type, followed by vascular dementia, which is caused by a disorder in the cerebral blood supply. Dementia can be also encountered in Parkinson's disease. Some types of dementia are typically accompanied by behavioural disorders as well (Pick's disease).

Currently, dementia is:

- one of the most common non-communicable diseases
- the main cause of disability and functional dependence of the elderly worldwide
- the seventh most common cause of death
- people suffering from dementia are estimated to have approx. seven to ten years of life left at the time of the first diagnosis

## Cognitive functions

Cognitive functions allow humans to perceive the world around us, to act, react and perform various tasks. Cognitive processes allow us to learn, remember, and adapt to the constantly changing conditions of our environment. In addition to memory, cognitive functions include also concentration, awareness, speech, speed of thought and the ability to grasp new information. The term executive functions describes the abilities to analyze and solve problems, plan and organize.

Dementia is characterized by pathological changes in the brain associated with a gradual loss of certain mental functions such as thinking, orientation, capability to learn etc., as well as with the decline of cognitive, emotional and social abilities. Short-term memory, thinking, speech and motor activities can also be affected, depending on the form and cause of dementia. Some forms of dementia can be accompanied by behavioural changes.

## Classification of dementia types

Dementia can be classified based on several criteria. Here, we will provide classification by origin:

- Primary degenerative dementia, arising from atrophic-degenerative processes,
- Secondary (symptomatic) dementia.

## Atrophic-degenerative dementia

Atrophic-degenerative dementia constitutes over 60 % of all dementia cases. It arises from processes reducing the number of neurons, malfunction of neurons as well as of the auxiliary neural (glial) cells and the decrease in the number of synapses (impulse-transmitting neuron connections). Atrophic-degenerative dementia is characterised by the formation

and accumulation of pathological proteins and several other degenerative processes. This neurodegeneration causes the brain to malfunction and subsequently leads to the development of dementia. Alzheimer's disease is the most common representative of this group.

## Alzheimer's disease

This type of dementia constitutes almost 70 % of all diagnosed cases. Typically, it affects people older than 65 years of age and its incidence (the number of new patients within a period) as well as prevalence (the proportion of individuals suffering from a disease in the studied population) increase with age. In most populations, it affects elderly women more often than men (the prevalence in the age category of 85+ in women is almost 50 %).

## Vascular (multi-infarct) dementia

Vascular dementia accounts for up to 20% of all dementias and is the second most common dementia after Alzheimer's disease. It is characterised by a loss of cognitive function resulting from brain damage caused by cerebrovascular or cardiovascular disease. Symptoms of vascular dementia usually appear within three months of the vascular event.

## Parkinson's disease with dementia

This type of dementia is characterized by impairment of all types of memory, particularly so-called explicit memory (also called declarative memory, defined as conscious recall of information, data and events from the past) and working memory (retaining certain information in memory for a very short period of time). In addition, executive functions (planning and control of complex motor capabilities are affected) and visual-spatial functions (problems with orientation and visual analysis) are also

impaired. In this type of dementia, speech impairment is less pronounced than in Alzheimer's disease. Hallucinations may occur in Parkinson's disease, but usually only as a consequence of pharmacological treatment. As in dementia with Lewy bodies, delusional thoughts (often eccentric jealous delusions) may occur.

## Dementia with Lewy bodies

After Alzheimer's disease, this is the second most common type of neurodegenerative dementia. In addition to the basic symptoms of dementia, dementia with Lewy bodies is characterised by fluctuating cognitive impairment, recurrent visual hallucinations, extrapyramidal syndrome (movement disorders) and, occasionally, delusions. In the 85+ age group, the incidence of this dementia exceeds 20 %.

## Pick's disease (frontotemporal dementia)

Pick's disease is the best known of the frontotemporal dementias. It is characterised by slow progression and is often associated with personality impairment. At the beginning of the disease, memory is usually not affected. Patients have problems with recollection and attention; executive functions, planning and visuospatial functions are markedly impaired. Social behaviour is often affected, with obvious emotional flatness. Fixed thinking is another symptom (the patient stays with one idea, concept or sentence, talking about the same thing over and over again).

## Huntington's disease

In Huntington's disease, dementia begins to manifest quite early – approximately in the patient's early forties. It is characterised by progressive deterioration in motor abilities, behavioural and cognitive skills. The patients suffer from anxiety and depression.

Other diseases associated with dementia include Creutzfeld--Jacob disease, normotensive hydrocephalus and Wernike--Korsakov syndrome.

## Degrees of cognitive impairment

- subjective memory deterioration,
- mild cognitive deficit,
- dementia (diagnosed by cognitive testing),
- mild dementia,
- moderate dementia,
- severe dementia.

Cognitive reserve capacity is a system that attempts to compensate for the losses and sustained neuronal atrophy that occur with ageing. It can be also perceived as resilience

to neuropathological damage, where the emphasis is on the way the brain uses its damaged resources. This capacity also allows individuals to cope and/or recover cognitive function after a brain injury or a psychotic episode.

## Risk factors of dementia

Dementia risk factors are conditions that increase the likelihood of developing one of the types of dementia, particularly:

- demographic factors (education),
- lifestyle (physical activity, cognitive activity, diet, sleep, smoking, alcohol, obesity),
- other diseases (high blood pressure, diabetes, atherosclerosis, high cholesterol, depression, arthritis, atrial fibrillation, cancer, hyperhomocysteinemia, kidney disease),
- medication (antihypertensives, statins, hormone therapy, non-steroidal anti-inflammatory drugs),
- environment (pesticides).

**Part 2:**

# Forms of dementia

## Warning signs and symptoms of dementia

When caring for the elderly, it is important to be aware of the most common symptoms associated with dementia that cause the patient difficulties in their everyday life. It is, therefore, important to be able to distinguish the warning signs of incipient dementia from the typical symptoms commonly associated with advancing age. The American Alzheimer's Association lists 10 warning signs that can alert family caregivers to symptoms related to Alzheimer's disease or other types of dementia.

**1. Memory impairment interfering with daily life**

Memory impairment is one of the most common symptoms of Alzheimer's disease, especially in the early stages. The elderly person forgets familiar information (where their clothes or food are kept), important dates or events. He/she asks the same questions repeatedly and has to increasingly rely on memory aids (written reminders) and family members to help him/her with activities he/she used to manage independently.

**2. Deterioration of planning and problem-solving abilities**

In elderly people with dementia, we may see a change in their ability to plan something and carry it out or to work with numbers. They may have trouble following familiar patterns or keeping track of their expenses. They are often unable to focus well on a particular activity, and, therefore, performing familiar activities may take much longer than they were previously used to.

**3. Impaired ability to perform familiar tasks**
Elderly with Alzheimer's disease may often have problems completing a task they used to do routinely. They may experience problems navigating around a familiar place, making a grocery list or remembering the rules of a favourite board game. They often cannot remember how to use certain household appliances.

**4. Impaired orientation to time and place**
Elderly with Alzheimer's disease and other types of dementia may have trouble perceiving time correctly. They lose track of the current date, time of day or season.
They may have trouble understanding things that are not happening right now. They forget where they are and how they got to a particular place.

**5. Difficulty perceiving visual images and spatial relationships**
In some elderly individuals, vision problems may be a sign of developing Alzheimer's disease. This can lead to balance or reading difficulties. Estimating distance and determining colour or contrast correctly may be also troublesome, causing problems with driving a car or riding a bicycle.

**6. Communication (speaking and writing) problems**
Elderly with Alzheimer's disease may have trouble following or joining a conversation. They may stop in the middle of a conversation (because they don't know how to continue) or keep repeating themselves. Vocabulary may be also affected – the individual may be unable to name a familiar object correctly or uses an incorrect name.

**7. Difficulty in putting things in the right place and a loss of the ability to recall procedures**
Persons with dementia may store things in unusual places. They are then unable to find them because they cannot recall

the activity they were doing. Therefore, they often accuse other family members or neighbours of stealing.

**8. Impaired or poor judgement**

The elderly may experience errors in judgment or decision-making. For example, they may have poor judgment in managing money or pay significantly less attention to their appearance and maintaining personal cleanliness.

**9. Loss of interest in work and social activities**

An elderly person suffering from the early stages of Alzheimer's disease may be aware of changes in their ability to maintain or follow a conversation. As a result, he or she may begin to cut back on hobbies and activities he or she used to enjoy and may withdraw from society.

**10. Mood and personality changes**
Elderly persons with Alzheimer's disease may experience changes in mood and personality. They may become confused, suspicious, depressed, fearful or anxious. They may become easily upset with family members or friends when they are in unfamiliar (uncomfortable) surroundings.

## Diagnosing dementia

To make a diagnosis, it is best to start with a visit to a general practitioner or neuropsychologist. At present, there is no test that would give a definite result. Diagnosis of dementia or Alzheimer's disease can be made by a doctor who is familiar with these diseases and has a set of supporting documents:

**Medical history** – a conversation between the doctor and the patient and his/her partner (family or friend). The professional needs to get as much information as possible from both parties. Therefore, if you are caring for a loved one, take his/her medical records and a list of any medications they are taking (including vitamins and supplements) to the doctor. Moreover, write down anything you find disturbing or strange in the patient's behaviour so as not to forget mentioning it.

**A careful clinical examination, supplemented with laboratory testing** – these aim predominantly to find out if the cognitive impairment might be due to a cause other than dementia. If in doubt, a neurological examination including CT and magnetic resonance of the brain may be performed.

**Blood and urine tests** – these are also carried out to rule out other diseases that could be causing dementia-like symptoms. The GP may refer the patient to other specialists for further investigations - a neurologist, geriatrician or psychiatrist.

Remember that the diagnosis takes time. The GP or specialist may issue a referral to a neuropsychologist who will then carry

out a series of diagnostic tests. Be prepared that the tests may be time-consuming – specific tests can take several hours but are essential to make a correct diagnosis.

If dementia or Alzheimer's disease are confirmed, it is important to seek out help. You may feel that you can easily manage everything on your own at first and there is time enough for that seeking help will come later. The first stages of the disease may be indeed mild. However, it is important to remember that your loved one's needs will change with the disease progression and you may find it difficult to recognize at what point help is no longer necessary. For this reason, it is best to agree the responsibilities with your family in advance. Think about who might be able to help, talk to the family about the illness and discuss with them the changes they may expect in their relative's behaviour in the future.

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**Part 3:**

# Preventing dementia

There is evidence that reducing exposure to certain risk factors is associated with preventing the onset of dementia. Research findings imply that lower incidence of dementia is observed in individuals who have regular physical activity and are actively involved in social life.

**Important preventive factors include:**

- regular physical activity (prevention of all types of dementia, any increase in current physical activity will likely slightly reduce the risk of dementia),
- social activity (number of social contacts and activities, prevention of social isolation),
- education (each year of education reduces the risk of dementia by 7% as it increases the cognitive reserve capacity),
- mental activity/workplace demands (high level of work complexity, mentally stimulating workplace),
- cognitively active lifestyle (cognitively demanding leisure activities, such as reading, playing games such as chess or card games, doing crosswords, possibly artistic activities,
- diet (Mediterranean diet: a balanced diet rich in fibre and fresh vegetables with unsaturated fats/olive oil/ fish and a limited amount of red meat; protective effects of unsaturated fats, antioxidants and vitamins B, E and C, flavonoids, niacin and folate, as well as of coffee and tea were found; in contrast, harmful effects of saturated fats and low vitamin D were demonstrated; weight reduction is also important),

- reducing or cessation of smoking and alcohol consumption,
- suitable treatment of chronic diseases (hypertension, diabetes, obesity, hearing impairment, depression),
- prevention of head injuries (helmet, protective equipment, precautions),
- limitation of anticholinergic treatment.

**General recommendations**

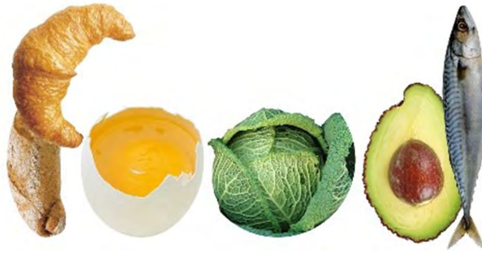
- regular physical activity and exercise are recommended at any age. An active lifestyle should be introduced from an early age and integrated into daily life,
- social integration is of utmost importance at any age. In older individuals, promoting social interaction and reducing loneliness becomes even more important, as these persons often experience loss on many levels (e.g. leaving a job or the death of a loved one),
- it is important to support formal and informal learning throughout life, from pre-school age to retirement, which

promotes the continuous development and improvement of knowledge and skills. Comprehensive formal education is an important foundation for further lifelong learning, increasing reserve mental capacity,

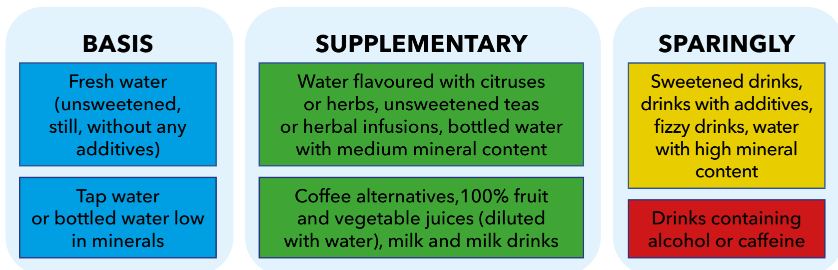
- an intellectually stimulating workplace also reduces the risk of dementia; increasing complexity, diversity and autonomy of the work can help prevent dementia,
- it is important to promote cognitively active lifestyle throughout life, for example by facilitating mobility for older individuals to improve their access to cultural events and institutions in remote areas,
- a diet rich in legumes, wholemeal cereals, fruit, vegetables and unsaturated fats (olive oil) and relatively high consumption of fish, moderate consumption of dairy products (mainly cheese and yoghurt) and low consumption of meat products is recommended,
- given the complex risk profile of alcohol, consumption should be reduced; young people should be prevented from starting to smoke and smokers willing to quit should receive support.

## Role of nutrition in preventing Alzheimer's disease

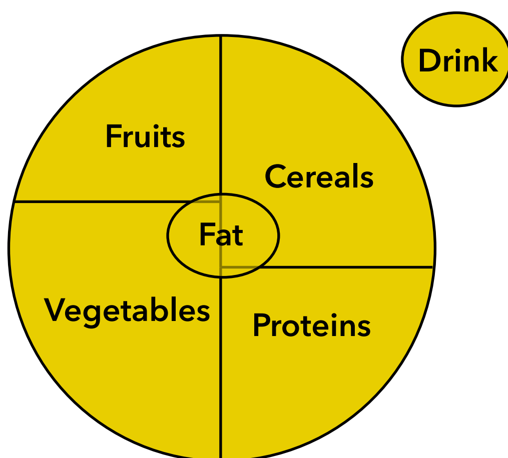
A varied and balanced diet forms the basis for the prevention of many chronic diseases. The term „varied diet" means supplying the body with all the substances important for its function (carbohydrates, fats, proteins, vitamins, minerals and water), while the term „balanced diet" means that these ingredients are supplied in the right proportion.



A healthy adult should drink approximately 30 ml of fluids/kg body weight daily. Fluid requirements may vary depending on the environmental conditions (temperature, humidity) and the health status of the individual (kidney and heart disease). The following diagram shows what fluids should form the basis of the drinking regime, what fluids should be used as supplementary and what fluids should be drunk sparingly:




Importantly, all the nutrients and water should be parts of each meal. Each meal should contain sources of carbohydrates, fat and proteins. Vegetables or fruit are also an integral part of every meal, representing sources of fibre, vitamins and minerals. Drinks can go along with the meals and/ or between meals. And what should a plate look like? Look at the picture:




To prevent Alzheimer's disease and other diseases of the nervous system, we should focus on sufficient intake of selected food groups, providing an optimal supply of vitamins, minerals and other beneficial substances:

| Food type | Foods | Benefits |
|---|---|---|
| Whole-grain cereals and products thereof | Wholegrain wheat, rye, oats, buckwheat, millet, wholemeal couscous, bulgur, brown rice, wholemeal pasta, barley and groats, spelt, amaranth, quinoa etc. | source of fibre, minerals, prebiotics |

| Food type | Foods | Benefits |
| --- | --- | --- |
| Green leafy vegetables | Lettuce and other types of salads, rocket, spinach, kale, cabbage, Chinese cabbage, sorrel, chard, chicory greens, asparagus, artichokes, celery, parsley, sprouts, etc. | These vegetables contain a lot of chlorophyll, which has magnesium in its structure. This, in turn, is very important for neural transmission |
| Berries | Strawberries, blueberries, cranberries, goji, grapes, gooseberries, chokeberries, currants, raspberries, blackberries, etc. | Excellent source of antioxidants |
| Nuts and oilseeds | Peanuts, walnuts, cashews, hazelnuts, macadamia nuts, pistachios, pine nuts, pecans, Brazil nuts, almonds, sunflower, pumpkin, sesame, chia, linen or poppy seeds, etc. | source of omega-3 fatty acids, fibre, protein, minerals and vitamins |
| Legumes and legume products | All types of beans, lentils, peas, chickpeas, soy and soy products - soy meat, tofu, tempeh, natto, sufu, etc. | source of omega-3 fatty acids, fibre, protein, minerals and vitamins; soy products are suitable for women because of their phytoestrogen content |

| Food type | Foods | Benefits |
|---|---|---|
| Fish and seafood | Salmon, mackerel, trout, herring, sardines, sprats, tuna, codfish, catfish, silver carp, shrimp, mussels, clams, squid, etc. | excellent source of protein, omega-3 fatty acids (especially EPA and DHA) and minerals (e.g. calcium) |
| Olive oil | Extra virgin, virgin, pomace | Excellent source of unsaturated fats, regulates blood cholesterol |
| Coffee or tea | All kinds of coffee, white, green, black or oolong tea. | Caffeine has antioxidative effects, as well as theaflavin in black tea or epigallocatechin-3-gallate in green tea |

Saturated fatty acids should be avoided. These fats negatively affect the condition of your vessels and increase blood cholesterol. Foods rich in saturated fatty acids include:

- **butter and fat spreads.** Replace butter and margarins with vegetable oils, primarily olive oil. The use of coconut and palm fat should also be limited – avoid them when preparing food!
- **cheese containing more than 30 % of fat and high-fat cream.** Consumption of cream sauces, cream and cheese soups should be limited. Instead of fat-based spreads, use legume-or vegetable-based spreads for bread or just sprinkle it with olive oil that may contain herbs or garlic,

- **fatty meats and meat products.** Prefer lean meat. Remove visible fat before cooking. Substitute red meat with poultry, fish or legumes,
- **fried foods** (i.e. the food is immersed in fat/oil during preparation), such as wiener schnitzel, chips, fried cheese, fried vegetables, fried fish, fried mushrooms, burgers, nuggets, fish fingers, sausages and smoked sausages, croquettes, fried rice and noodles, etc.
- **sweets and sweet pastries.** Prefer low-fat sweets (candies, sorbets, jellies, etc.). Also, limit the intake of foods and drinks sweetened with artificial sweeteners. Try to replace sweets with fruit (including berries).

It is also advisable to regulate the amount of salt in the diet. Five grams is the recommended daily intake of salt. Of this, 4 g comes from foods containing ‚hidden salt', such as baked goods, meat products, cheese, pickled products and salty snacks. The use of salt during cooking or its addition to ready meals are other significant sources of salt in the diet. Here are some suggestions on how to reduce the intake of salt:

- **cook meals at home** from basic fresh ingredients (avoid using ready-made meals) and eat at home more often than in restaurants etc. to control the amount of salt,
- **reduce the use of salt-containing flavourings** and sauces in cooking/dining,
- partially replace salt with **fresh or dried herbs** (ideally, also monitor the salt content in seasoning mixes and prefer those without salt),
- **do not add salt to meals on the plate,**
- if canned food is used, it is advisable to **remove excess brine and rinse the contents of the can,**
- cook rice, potatoes, pasta and various other cereals in **unsalted water**,
- replace breakfast cereals with **cereal flakes.**

- use **salt substitutes** (containing often potassium instead of sodium),
- **remove the salt shaker** from the table,
- limit salt intake **early in your life**/do not start using much salt,
- **gradually** reduce the used amount of salt,
- increase the intake of **fresh fruits and vegetables,**
- avoid **salty snacks,**
- read **food packaging information,**

Should you wish to learn more about the diet preventing the development of Alzheimer's disease and other neurological diseases and receive individual dietary advice, contact the Nutrition Centre at the Faculty of Medicine of the University of Ostrava https://nutricniporadna.osu.cz/

**Part 4:**

# Tips for caring for loved ones suffering from dementia

## Verbal communication and dementia

Dementia affects each individual differently. It is, therefore, important to communicate in the way that is most appropriate for the particular person. We need to listen carefully and consider what we want to say and how we want to say it. In addition to difficulties with using words, people with dementia often have visual and hearing problems that also make communication difficult. They experience ups and downs in concentration and communication skills (affected by fatigue, ill health, noisy environment, etc.). If a person with dementia is unable to communicate in their usual way and cannot express what they want in words, they lose confidence and become anxious, depressed and withdrawn.

Changes in communication that can be noticed:

- the patient speaks less than used to be normal,
- difficulty finding the right words,
- difficulty pronouncing words,
- making up new words to replace words he/she has forgotten,
- repeating words or whole phrases he/she hears,
- difficulty in ordering words into logical sentences,
- using the language the patient first learned in childhood (e.g. the patient starts speaking only German instead of Czech).

As dementia progresses, it becomes increasingly difficult to understand the needs, wishes and emotions of the person

we care for. Although communication is becoming more challenging, there are many ways to communicate in a meaningful way. We should remember the following:

- reduce/eliminate distractions when communicating (turn off devices, close the windows),
- explain why it makes sense to turn off the TV, close the window,
- choose an appropriate time of day when the person with dementia is able to communicate most clearly,
- assess the current state (health, psychological),
- make sure the needs of the person with dementia are satisfied (no pain, hunger, thirst or need to go to the toilet),
- remember the preferences of the person with dementia,
- choose a topic for conversation or activities that the person with dementia will enjoy,
- offer options you know the person will like,
- focus on what they can do, not on things they can't do.

Remember that good communication is an important part of quality of life in dementia. It helps the individual maintain a sense of self-identity and social relationships.

## Non-verbal communication and dementia

If any verbal communication (conversation) becomes too difficult for a person, non-verbal communication, which includes gestures, facial expressions and body language, can be used. For people in the more advanced stages of dementia, it can become the main mode of communication. Touch (holding hands) can be used for communication at this time; some people with dementia like to express themselves by drawing or singing.

Tips for non-verbal communication:

- use physical contact to express interest and support (holding hands, hugging),
- try to recognise what the person with dementia is trying to say with their body language,
- respect personal space when communicating and try to stand/sit at eye level,
- your body language and facial expression should match what you are saying (it is appropriate to smile when describing pleasant memories),
- sudden movements and tense facial expressions can upset the person with dementia, even if the content of our narrative does not upset them,
- use visual cues (pictures, videos of different types of food) to allow the person with dementia to express their choices (e.g. which food they like),
- allow them to express themselves by drawing.

## Nutrition in severe forms of dementia

Complications of advanced dementia include malnutrition and dysphagia. Malnutrition in severe forms of dementia is characterised by unintentional weight loss. It leads to a greater susceptibility to infectious diseases, impaired wound healing, bedsores and fractures. The Body Mass Index

(BMI) is a quick tool for diagnosing malnutrition. It is calculated using the equation:

$$BMI = \frac{\text{person's weight in kg}}{(\text{person's height in m})^2}$$

BMI below 18.5 $kg/m^2$ in people under 65 years and below 20 $kg/m^2$ in people over 65 years indicates a risk of malnutrition and a doctor or nutritional therapist should be contacted.

Treatment of malnutrition lies in three steps, depending on the individual's condition:

1. A nutritious diet with increased energy and protein intake.
2. A nutritious diet with the addition of dietary supplements.
3. Introduction of enteral or parenteral nutrition in combination with a nutritious diet.

## Nutritious diet with increased energy and protein intake

- it is important to increase the energy density in the food,
- to increase the intake of fat, which serves as energy supply and improves the taste of food,
- to serve high-fat dairy products and cheese, meat products containing fat, fatty fish, whole eggs,
- to add fat to ready meals and side dishes (butter and vegetable oils such as olive oil are best),
- we should serve vegetables as salads with oil, mayonnaise or other high-fat dressings,
- fruit should be served with high-fat milk products, ice cream, pudding, chocolate, etc.,
- bread and bakery products should be spread with fat (butter, avocado, drizzled with oil or dipped in it),

- add nuts and seeds – whole or ground – to dairy products, salads and porridge, use nut butters in dishes and on baked goods,
- avoid burnt (oxidised) and rancid fats (e.g. old nuts),
- we can also increase energy intake by adding carbohydrates, preferably sugars – the sweet taste is often well tolerated by elderly people with dementia,
- sweet foods can be in reasonable amounts used even in malnourished patients with diabetes,
- add honey, jam, sugar to drinks, dairy products, fruit, porridge,
- add soaked dried fruit in dairy products, puddings, porridges, rice, desserts, or boil it in sauces,
- serve sweet dishes (with added fat), sweet fat pastries, fatty sweets (chocolates, bars, candies),
- it is also very important to have enough protein in the diet,
- protein-containing foods should be served at least twice a day,
- animal proteins, such as meat and meat products, milk and dairy products, eggs, and fish should be the primary sources of proteins (at least 1 portion per day),
- plant proteins (legumes – kidney beans, peas, lentils, chickpeas – and soya products (tofu) should be included several times a week,
- powdered milk or egg (white) can be added to the dishes, such as porridge, soups, sauces, etc. to increase the protein intake,
- meals should be served regularly at 2–3 hour intervals, the patient should eat even if he/she is not hungry,
- at least 5 meals a day should be served: breakfast – snack – lunch – snack – dinner,
- second dinner should be added about two hours before bedtime.

For an individualized diet plan, contact a nutritional therapist.

## Nutritious diet with the addition of nutritional supplements

The term oral nutritional supplements (or sipping supplements) describes a complete and balanced liquid diet developed for patients with increased energy and nutrient needs. The preparations are administered by mouth and are intended to supplement the normal diet, not to replace it. They are usually sold in 125-300 ml bottles, with one bottle containing enough energy and protein to cover on average half of an adult's normal lunch portion. Sipping should, however, not replace standard meals but supplement it. It is also advisable to sip preparations slowly over an extended period of time to prevent the onset of indigestion.

Diet can be also fortified with modular dietetics – liquid or powdered individual nutrients (protein, carbohydrate and fat) that can be added to food or drink. Consult your doctor or nutritional therapist about taking nutritional supplements.

**The introduction of enteral or parenteral nutrition in combination with a nutritious diet** involves the administration of liquid nutrition via a tube or stoma (into the stomach or small intestine) and/or the administration of nutritional solutions directly into the venous system (infusion). This type of nutritional intervention is indicated by the physician in severe conditions of malnutrition or other digestive disorders and diseases.

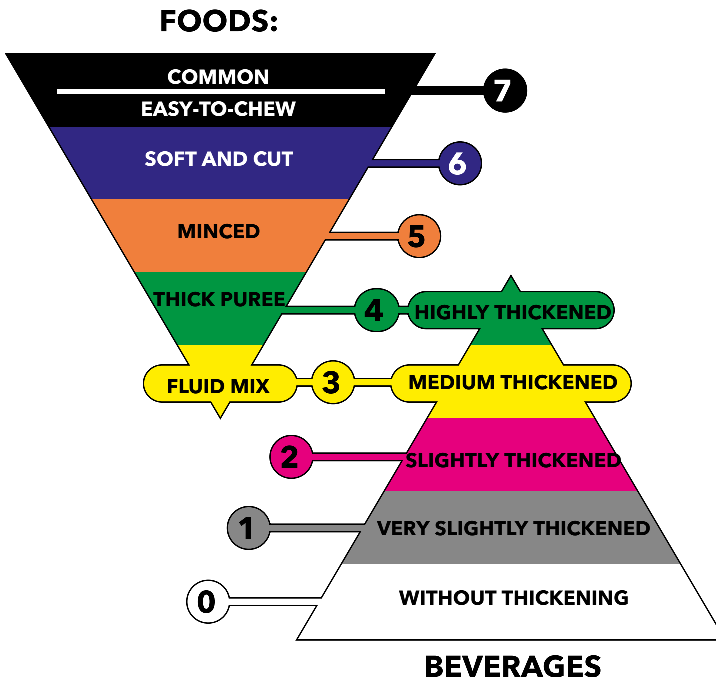
**Dysphagia** is a swallowing disorder that affects the ability to ingest food of certain consistency, liquids, medications, or even to swallow saliva. It can manifest through the following symptoms:

- guttural voice,
- drooling,
- cough with gagging,
- dysphonia (inability to produce sound),
- dysarthria (speech disorder),

- reflux (heartburn),
- odynophagia (painful swallowing),
- aphagia (inability to swallow).

Swallowing disorders can lead to food entering the airways and lungs and cause inflammation (pneumonia). If dysphagia is not treated early and appropriately, it can lead to malnutrition and dehydration.

Persons with dysphagia require a diet with a modified texture of foods and beverages. The degree of dietary modification depends on the degree of dysphagia (determined by the clinical speech and language therapist). The different types of texture modification of food and drink are shown in the figure:




Special maltodextrin-based preparations, called thickeners, are used to thicken liquids and are commonly sold in pharmacies. These odourless and tasteless powders can be added to liquids and food (water, hot and sweetened drinks, soups, etc.) to aid

individuals who are unable to regulate the swallowing of liquids. The degree of fluid thickening is individually determined by a clinical speech therapist in collaboration with the nutritional therapist.

The consistency of food can be also adjusted, again based on an individualized prescription by a speech therapist and nutritional therapist.

Further guidance for people with swallowing disorders is provided in the table below:

| Problem | Consistency | Try to avoid |
|---|---|---|
| Difficulty chewing | Soft and minced foods | Hard foods: tough meats, hard fruits and vegetables, bread crust |
| Difficulty handling food in the mouth | Soft foods | Hard, grainy or crumbly foods, thin liquids |
| Too little saliva | Soft and liquid foods, drinking liquids while eating | Dry foods |
| Choking on liquids | Thick and/or thickened liquids | Thin liquids |
| Difficulty swallowing | Liquid and soft foods | Tough and hard foods |

Appropriate assistance with feeding is, along with preparing appropriate food and drinks, very important for people with dementia and dysphagia. The following steps should be followed each time food is fed:

- make sure the person is awake and responsive,
- get the person into a sitting position,
- check the contents of the mouth, clean as necessary,
- prepare all necessary cutlery and utensils beforehand,

- check the consistency of foods and drinks,
- check swallowing by Adam's apple movement,
- assist with swallowing if needed (cheek massage, spoon pressure on tongue),
- put liquids and solid food separately into the mouth, checking the contents in the mouth,
- when coughing, do not give the patient water,
- check the contents of the mouth after the end of feeding and clean the food residues in the mouth as necessary,
- keep the person seated after eating for at least 30 min.

In severe forms of dementia, there may be other problems related to nutrition:

## Constipation

- an adequate fibre intake needs to be ensured (25-30 g/day); if dietary intake is inadequate, include fibre supplements such as Psyllium,
- sufficient fluid intake is necessary (1.5–2 L/day, primarily plain water, secondarily water flavoured with mint/lemon, herbal and fruit teas, low-mineral bottled waters, less often juices, flavoured teas and mineral waters, sweet drinks),
- physical activity – 30 minutes of moderate intensity (activities during which the patient can still breathe easily),
- regular meals (do not skip meals),
- probiotics (beneficial bacteria from fermented milk products).

## Slow stomach emptying, gastroparesis

- serve smaller meals but more often,
- reduce the intake of foods rich in fat,
- drink plenty of fluids, but avoid fizzy and concentrated drinks,
- - use liquid food instead of solid,
- - reduce the amount of fibre if you have a high fibre intake,
- - consult a nutritional therapist!

Part 5:

# How to cope with the care

It is not always necessary to carry the whole burden of caring for people with dementia alone. There are a number of facilities that can help you care for your loved one.

## Day-care homes

Day-care centres provide outpatient services for people who cannot manage daily activities independently due to age or disability as well as for people with a chronic mental illness who need regular help from another person.

The following basic activities are typically provided:

- assistance in coping with everyday tasks,
- assistance with personal hygiene or provision of conditions for personal hygiene,
- meals,
- educational, training and social activation activities,
- socializing,
- social therapeutic activities,
- assistance in exercising patient's rights and legitimate interests and in managing personal affairs.

## Day-care centres

Day-care centres provide outpatient services to persons with limited self-sufficiency due to age, chronic illness or disability and whose situation requires the assistance of another person. The mission of the day centres is to provide support, care and activities for people with disabilities

(particularly dementia or Parkinson's disease) at the time when they cannot be cared for by family members or other close relatives, thus prolonging their stay in their natural home environment. The centres usually operate only on weekdays during pre-set opening hours. The service includes assistance with personal hygiene or the provision of conditions for personal hygiene, provision of food or assistance in providing food, educational, training and activation activities, mediation of contact with the social environment, social therapy activities, and assistance in exercising patient's rights and legitimate interests and managing personal affairs.

## Short-term residential care home

Typically, these care homes offer respite care for one working week to persons with reduced self-sufficiency due to age or disability and to persons with chronic mental illness whose situation requires regular or even constant assistance. These residential homes generally operate during the working week, from Monday morning to Friday afternoon. The main aim of this service is to provide help and support to people with reduced self-sufficiency by providing housing with all the facilities and care provided. The staff of the residential home strive to promote the independence of the clients as much as possible, promoting their personal potential. The service includes assistance with all activities of daily living – provision of meals, accommodation, assistance with personal hygiene or provision of conditions for personal hygiene, assistance in coping with the normal tasks of personal care, educational, training and activation activities, socializing and social therapeutic activities as well as assistance in exercising rights and legitimate interests and in managing personal affairs.

## Residential care homes

Nursing homes for the elderly provide residential care to persons with limited self-sufficiency (mostly) due to age and whose situation requires regular assistance from another person. The mission of a home for the elderly is to provide dignified and empathetic assistance, support and care to the elderly. The aim is to ensure that the elderly can live a peaceful old age, if possible with constant contact with their loved ones. The service includes help with all standard daily activities – provision of accommodation and meals, assistance with the normal tasks of self-care such as personal hygiene or the provision of conditions for personal hygiene, contact with the social environment, social therapeutic and activation activities, and assistance with exercising rights and legitimate interests as well as the management of personal affairs.

## Specialized nursing/care homes

In these homes, residential services are provided to individuals with chronic mental illness, drug abusers, or persons with dementia of any type including Alzheimer's disease whose self-sufficiency is limited and whose situation requires regular or constant assistance. The regime in these institutions for the provision of social services is adapted to the specific needs of the respective groups, depending on the type of patients the particular home cares for. The service includes assistance in managing all normal daily activities – assistance with personal hygiene and self-care, provision of meals, accommodation, contact with the social environment, activation activities, social therapy activities, as well as assistance in exercising rights or managing personal affairs.

## Home care agencies

Home care agencies provide health care for individuals with chronic illnesses. They provide comprehensive

health and nursing care to clients of all ages in their home environment. The attending GP decides about the suitability of home care for the particular patient. In home care, carers visit their clients to help them with self-care, hygiene, dressing, eating, cooking, and household maintenance. The carers also act as escorts to doctors, offices, cultural activities, rehabilitation, etc. This type of care focuses mainly on patients with chronic illnesses, both physical and psychological. In addition, home care is provided for people who are in the terminal stages of their life. However, if recommended by a doctor, preventive home care is also possible for monitoring sudden changes in health (e.g. critical blood pressure or blood sugar levels). Every citizen of the Czech Republic is entitled to home care, provided that they receive a referral from their doctor and have health insurance, which covers home care in full. A caregiver can come up to three times a day for one hour. However, the patient may need special equipment necessary to allow him to stay at home and use the help of home care. Such equipment is, unfortunately, usually only partially covered by health insurance. It is, however, possible to apply for other forms of help (care allowance) to cover these costs.

## Care services

A care service is an outreach or outpatient service provided to people with reduced self-sufficiency due to age, chronic illness or disability, and to families with children whose situation requires the help of another person. The service provides the listed tasks at defined times in the persons' homes. It enables its clients to remain in their familiar home environment and to live in the way to which they are accustomed for as long as possible. This type of service always seeks to provide a level of support that preserves and develops the client's abilities as much as possible while aiming to reduce the patient's dependence on the help

of others. The service includes help with all activities of daily living – help with personal hygiene and self-care, provision or help with preparing meals, arranging for the administration of medication, facilitating contact with the social environment, and helping to run the household. A list of all care services by region can be found on the website of the Ministry of Labour and Social Affairs, specifically in the Social Services Register.

## Psychiatric outpatient clinics

These medical facilities help patients with mental illness. A psychiatric outpatient clinic is often a patient's first point of contact with psychiatric care. This contact is very often long-term and continuous. Psychiatrists can – as well as neurologists or geriatricians – prescribe medication for Alzheimer's disease. If outpatient treatment is not enough, the doctor will recommend treatment in an inpatient ward of a psychiatric hospital. A list of psychiatric outpatient clinics is available at the link below, or again in the National Register of Health Service Providers.

## Neurological outpatient clinics

A neurological outpatient clinic performs complete diagnosis and treatment of a wide range of diseases of both the central and peripheral nervous system and associated structures. These clinics also provide treatment of diseases of the brain and nervous system, focusing also on diseases affecting the physical self-sufficiency of the patient - mobility, proper organ function, etc.

Upon arrival at the neurological outpatient clinic, the patient undergoes a basic examination. During the first visit to the clinic, the doctor collects basic information, such as the presence of related diseases in the patient's family. He then focuses on the nature of the patient's problems, their duration and associated complications. In subsequent appointments,

the doctor evaluates the progression of the symptoms over time. Neurologists as well as psychiatrists and geriatricians can prescribe medications for Alzheimer's disease. A list of neurology practices is listed within the National Registry of Healthcare Providers.

## Geriatric outpatient clinics

Geriatric outpatient clinics provide care for elderly people with chronic illnesses, mainly those with multiple organ involvement, focusing on caring for patients with early signs of dementia. Geriatric outpatient clinics provide diagnosis, treatment and long-term follow-up of patients, aiming to maintain the best possible self-sufficiency into old age and to prevent serious diseases of old age. These clinics also evaluate the health of the elderly before major surgical procedures. Geriatric outpatient clinics specifically care for elderly patients, usually over 65 years of age. They comprehensively deal with health problems arising in relation to old age, regardless of whether these problems are of physical or mental character. A list of geriatric outpatient clinics can be found on the website of the Czech Society of Gerontology and Geriatrics.

**Part 6:**

# Planning ahead: legal and financial aspects

## Care allowance and other financial support

The care allowance is intended for people who, because of a long-term adverse health condition, need help from another person to cope with the basic needs of life. The allowance can be used to pay for help provided either by a close person or by a registered social service. In the case of people with dementia, such help can be represented by home care services or day-care centres. If the person with dementia stays in a long-term residential nursing home, the care allowance is payable to the facility.

In 2023, the allowances for individuals of 18 years or older are:

880 CZK for Grade I (mild dependence),

4,400 CZK for Grade II (moderate dependence),

12,800 CZK for Grade III (severe dependence),

19,200 CZK for Grade IV (total dependence).

More information on the care allowance and the application procedure can be found on the website of the Labour Office https://www.uradprace.cz/prispevek-na-peci, where electronic forms are also freely available for download.

You can also apply for the so-called disability benefits, which include the mobility allowance, assistive devices allowance

and disability cards (TP, ZTP/P card). More information about these benefits can be also found on the website of the Labour Office.

## Assistive devices

A majority of the assistive devices (e.g. crutches, walkers, wheelchairs, electric adjustable beds, or aids for easier hygiene) are partially or fully paid for by health insurance. They are usually prescribed by the attending GP or a neurologist. Assistive devices can be acquired from medical supply stores, some even from pharmacies. Most hospitals and some charities or social services offer the possibility to lend the device.

## Continence aid allowance

Continence aids (insert pads, nappy inserts, fixation pants, bed pads etc.) can be prescribed by a GP, urologist, neurologist, or geriatrician for a period of up to 3 months.

## Long-term „care for a family member“ allowance

This benefit allows people to stay at home while caring for a family member whose attending physician at a healthcare facility providing inpatient care (usually a hospital) has determined that his or her health condition requires home care after discharge from hospitalization. Long-term „care for a family member“ benefits will also provide room for any subsequent decisions the family may make about how to care for their loved one if they can expect him or her to continue to require care. One option would be to apply for a care allowance under the Social Services Act.

The „care for a family member“ allowance should be applied for by the attending physician at the healthcare facility where

the patient was hospitalized for at least 7 days, provided that the patient will need long-term care for at least 30 more days.

For more details, please visit the Czech Social Security Administration website: https://www.cssz. cz/dlouhodobe-osetrovne

## Legal capacity and its restriction

The Civil Code defines the legal capacity in Section 15(2) as the capacity to act legally, i.e. to to act with one's own legal rights and commit to the duties. If it is in the interest of the person suffering from dementia and the legal conditions are met, the court may decide to restrict the person's legal capacity.

It is essential to mention that the legal capacity cannot be revoked (unlike in the original regulation of the Civil Code of 1964) and the person cannot renounce his/her legal capacity. Legal capacity can only be limited. The court can only limit the legal capacity to the extent corresponding to the person's incapacity of acting. At the same time, it should be added that a person's capacity to act unlawfully cannot be limited in this way but must be assessed individually for each case after an unlawful act has been committed.

The grounds on which the person's legal capacity is to be restricted and, above all, the extent to which it is to be restricted must be set out in detail in the application for restriction of legal capacity. The application shall also be accompanied by a medical opinion or a medical report on the state of health of the person concerned. If such evidence is not submitted to the court, the court may reject the application.

Many other useful tips can be found on our project website https://www.zijemesdemenci.cz/

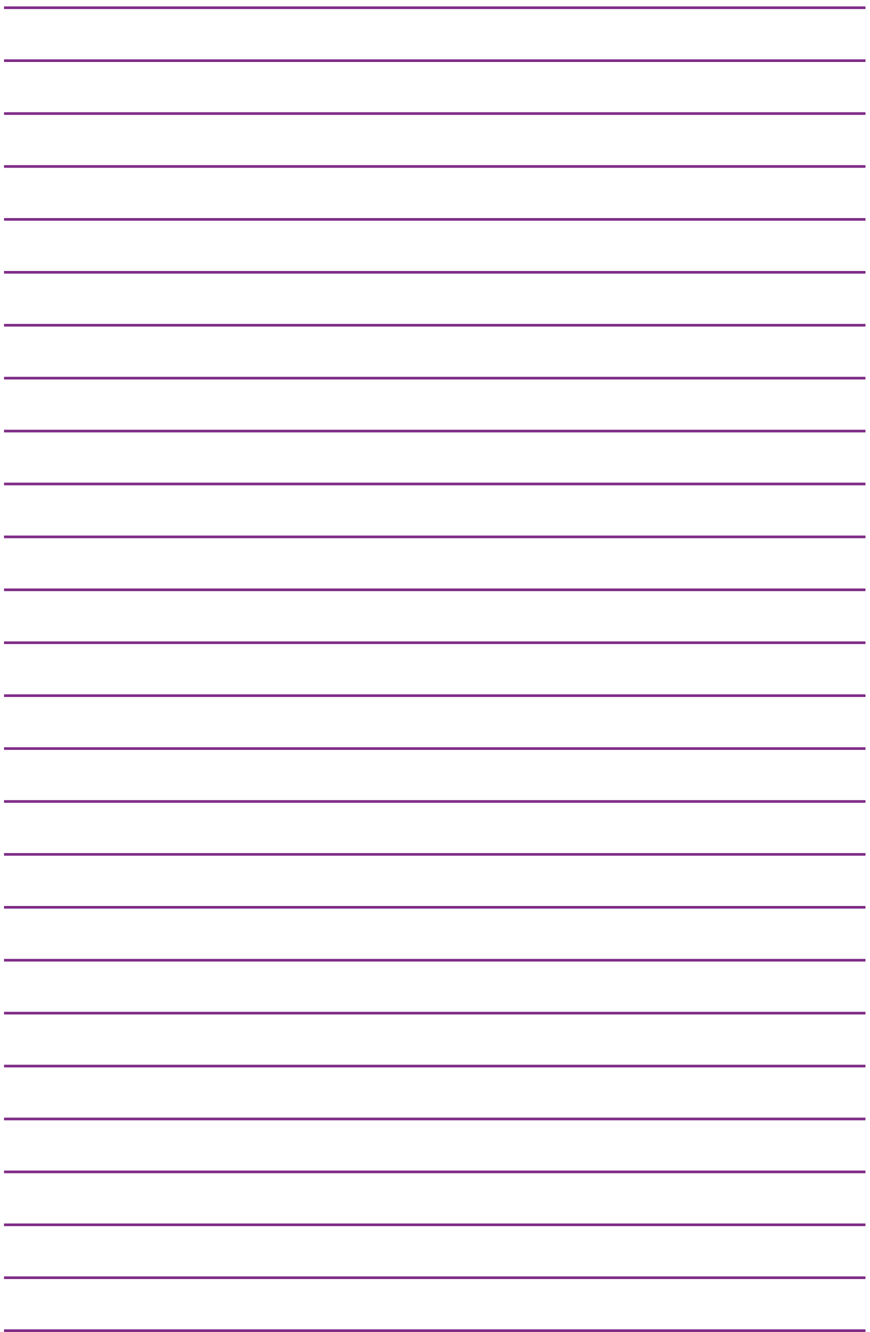
# Summary

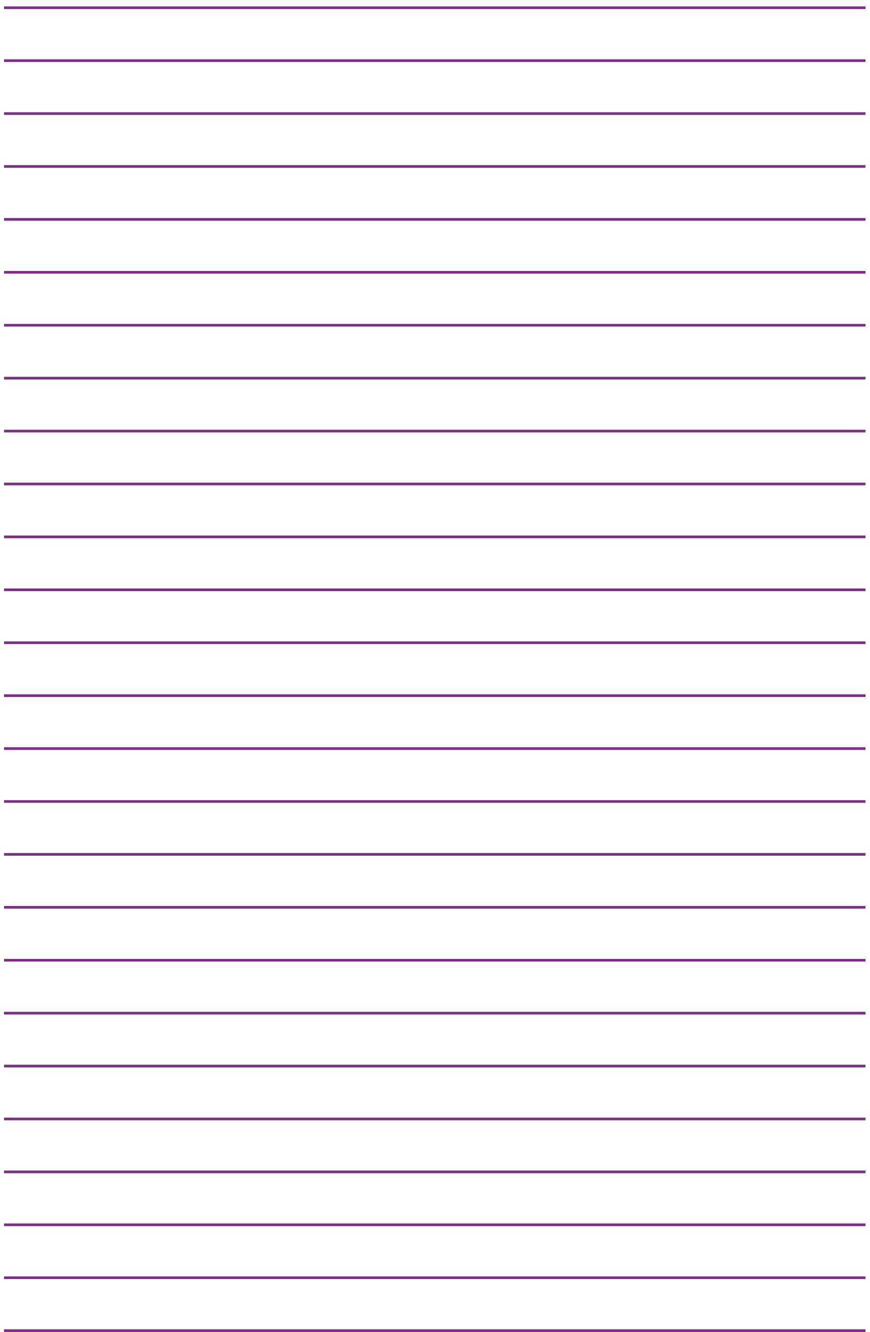
## Acceptance, hope and support

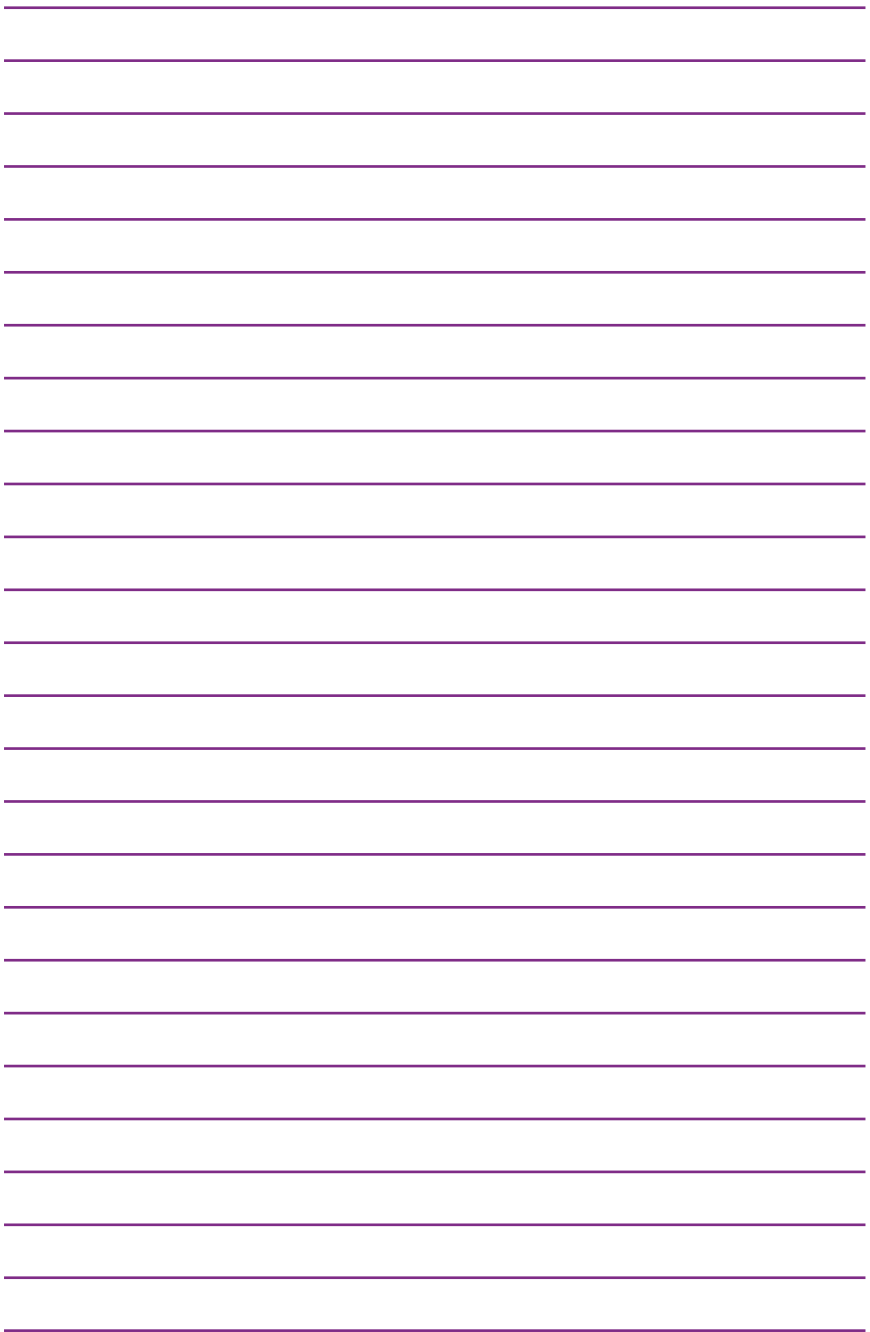
Thank you for taking the time to read this booklet, which aims to promote understanding of dementia and practical tips. Knowledge and empathy are powerful tools in the face of everyday challenges. Dementia affects not only the patients suffering from this disease, but also their families and communities. However, amidst the complexity of the condition, there is still hope, human resilience and the strength to adapt to the new needs of loved ones.

Remember that individuals with dementia continue to have unique characteristics, experience emotions and have a lifetime of experience that deserves recognition. With support, understanding, patience and empathy, we can create an environment that will improve their quality of life.

It is also essential to support all persons who are close to the patient and to use the help of professionals, support groups and available resources. As research and medical advances grow, so does our ability to improve the lives of people with dementia. Together, we can break through the stigma surrounding dementia and help create a society that provides inclusion for all affected, valuing the dignity and humanity of each individual.







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ŽIVOT S DEMENCÍ

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prof. MUDr. David Skoloudik, Ph.D., FESO, Mgr. Nadezhda Borzenko,
doc. PhDr. Mgr. Helena Kisvetrova, Ph.D.

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