

Together in caring for a person with dementia



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Dear readers, informal caregivers, you are holding a brochure aiming to provide you with information and support in the challenging task of caring for a sick person at home.

The disease of dementia fundamentally changes the lives of both the ill person and his/her loved ones. Family support, stable environment, informal home care and the use of professional services enable the patient to live a better quality of life.

Any of us can find ourselves in a situation where dementia enters our lives or those of our loved ones. Mrs Jana, whose story is presented on the next page, will guide you through the brochure „Together in caring for a person with dementia“.

You'll learn what it's like to be a carer for someone with dementia, what are the options in caring for your loved one, including practical advice and recommendations from people who have been or still are in the caring role. It is very important to realize that you are not alone in your caring role. You can get help with your difficult situation from professional social and health services who can provide care for your loved one at home or, temporarily or permanently, in a residential care setting.

Before our guide Jana introduces you to the practical side of informal home care through her own story, we will provide you with information about the disease of dementia, its symptoms, risk factors and stages on the first couple of pages. We firmly believe that the information in this brochure will help you to cope with your caregiver role and bring about an improved quality of life for both your loved one - the ill person - and you!

We wish you a lot of strength and patience!

For more on the topic of dementia, visit:

www.zijemesdemenci.cz

Caregiver - still the same person on a new path



My name is Jana. I'm 45 years old. I have a husband and two children aged 14 and 12. I work as an accountant in a private company. My parents live about 50 km from us. They have always been very helpful.

*I feel very grateful to them. They were both healthy retirees who enjoyed their time off and their grandchildren. They always had lots of friends. Until recently, they travelled all over Europe. My mother, who celebrated her 75th birthday last year, started to be forgetful a few months ago. At first, we laughed about it. Then she got lost at a shopping centre, a place she knew well and went to regularly. Moreover, she started acting strange, as if it wasn't her - putting her shoes in the fridge, forgetting ingredients when cooking, or sitting alone in her room in the dark for hours. She used to laugh a lot and talk to us. But then, she started avoiding us. It was like she wasn't interested in us. Sometimes she'd cry for no reason. The GP called by my daddy recommended a neurological examination. But Mom refused to admit that anything was wrong. She wouldn't go in for an examination. She even started accusing us of conspiring against her. We stopped laughing. Her forgetfulness wasn't funny anymore. After a few weeks of intense persuasion, she and Dad visited a neurologist. I remember the day Dad called. I was driving the car. I had to pull over. My mom, a university graduate, loving wife, mother, grandmother, friend, aunt...has **Alzheimer's disease**. My dad was crying on the phone. We're both scared of what lies ahead. Are we gonna make it?*

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Symptoms of dementia

We are in daily interaction with other people in dealing with our affairs. Most often, we are in contact with our family and close friends. Behavioural changes are often very difficult to detect, especially in the early stages of an illness. In the beginning, the stories about forgetting something somewhere may be funny. However, if situations involving memory loss that may endanger the person's health begin to occur, the situation needs to be addressed.

The characteristics of a person with dementia vary. These persons may be characterised by strange and unusual behaviour, memory problems, especially repetitive behaviour or not remembering names. There may also be difficulties in learning new things, behavioural disturbances, impaired orientation and an inability to make decisions for themselves.



Behavioural changes depend on the stage of dementia the person being cared for is currently in. The basic classification is:

- **Mild dementia** - short-term memory impairment, problems with body coordination, unsteady gait.
- **Moderate dementia** - long-term memory impairment, loss of self-care skills, loss of interest in former hobbies/favourite activities, impaired orientation to place, time and person.
- **Severe dementia** - inability to sustain any activity, inability to recognise family members or even the own image in the mirror.

A person who has dementia notices significant changes in their daily functioning and feels confused about his/her progressing condition.

In particular, the following areas are involved:

- Inability to cope (short-term memory impairment - „I don't know how to do this“).
- Identity (Is it „me“?; long-term memory, my life history).
- Social isolation (communication disorder, stigma - „I am in the way“).
- Loss of control (disappearing „me“, „I don't know what I'm doing“, „I don't know who I am and how I got here“).

The following diagram shows how to distinguish accidental forgetfulness from the serious condition of your loved one.



Schema 1: Symptoms of dementia

Risk factors of dementia

A caregiver practically cannot influence the occurrence of risk factors for dementia in their loved one. In many cases, he or she is already in the position of caring for someone who has already developed the disease. However, knowing the risk factors that can affect or exacerbate a person's condition is very important for the carer.

By risk factors for the development of dementia, we mean conditions that increase the likelihood that a person will develop some type of dementia. Not all factors can be influenced by the persons themselves; an active approach to risk factors can, however, help reduce or delay the development of dementia.



Uncontrollable risk factors include:

- age,
- sex,
- genetic predispositions.

The organization Alzheimer's Disease International has identified potentially modifiable risk factors and classified them into four key areas:

- developmental factors,
- psychological and psychosocial factors (such as depression, sleep disorders, social isolation),
- lifestyle-related factors (e.g. smoking, alcohol, physical activity, food),
- cardiovascular risk factors (such as arterial hypertension, diabetes mellitus, dyslipidemia, obesity),

Modifiable factors include also severe head injury causing damage to the brain.

Stages of dementia

In the day-to-day care for a person with dementia, the caregiver is aware of the irreversibility of the person's physical and, especially, mental health. The person's condition may change from day to day. For this reason, the carer must be prepared for sudden changes in behaviour and adapt care accordingly.

1st Stage - onset of dementia

In the early stages of dementia, the symptoms are mild, easy to miss and often downplayed by the patient and the family. At this stage, the person is still relatively independent. He or she needs only occasional supervision by family members (telephone consultations, instructions, reminders).

The person is aware of his/her illness at this early stage. In reaction to this, he may express sadness, fear or anger. He becomes insecure, distrustful and suspicious. It is, therefore, necessary to ensure that the person receives as much information as possible in a way that he or she can understand. Keeping to a regular daily routine and maintaining the rituals to which he or she has been accustomed in life can help with time orientation. A regular routine gives him a sense of security, while any changes confuse him.

2nd stage - moderate dementia

The duration of this stage can differ among types of dementia; for example, it is usually two to ten years in Alzheimer's disease. At this stage, patients already need constant supervision because their self-sufficiency is affected and they need help

with normal daily activities. They usually do not have serious behavioural problems such as restlessness or aggression.

At this stage, patients are still able to perform various activities (programme activities) within the day schedule and benefit from them. Activity programming is useful for family caregivers as well because it allows the patient to be in their own social environment for as long as possible. It is also important to allow the patient to make simple decisions for themselves. However, this stage is already challenging for family carers because the patient's dependence on family care increases. Often, the patient must move permanently to live with the family. If the patient is left alone, sooner or later he or she develops self-neglect. Food and fluid intake is impaired, leading to malnutrition and dehydration, the patient may fail to take medication (risk of exacerbation of chronic illnesses) and often has a disregard for dressing, wearing clothing not matching the weather conditions and the season.

Stage - severe dementia

This stage is characterised by significant impairment of memory as well as of other cognitive functions. The patients also develop other health problems, causing a general weakening of the patient's body and a greater susceptibility to infections (e.g. flu, pneumonia, kidney and urinary tract infections).

Patients with severe dementia are characterised by total dependence on the care of others. The everyday care in the home environment is very demanding and requires the coordinated cooperation of the whole family. Progression of wasting (geriatric frailty) is usually observed. It is not possible to determine in advance how quickly this stage of dementia will progress, nor which symptoms will be the most pronounced. In order to preserve the patient's quality of life to the maximum, social contact and respect must be ensured even at this stage of dementia.

Starting to care for a person with dementia

At the beginning of the period of caring for a loved one with memory impairment, **confirming the diagnosis** is the first important thing to do. For this, it is necessary to obtain the opinion of a specialist doctor, preferably a psychiatrist or neurologist.

The information or confirmation that a loved one has dementia has a major impact on our lives. Not only on the life of the person with the disease and the caregiver but on the lives of the whole family. Each family member is affected by this change.

Family support is the best we can do for the patient (delaying institutional care, supporting their independence, preserving memories and bonds with loved ones as well as stereotypes, habits).



Where to ask for information, support, help and advice

When you find out that your loved one has been diagnosed with dementia, it is important to get information that will help both the carer and the person with the condition to find their way. The Internet is a useful source of such information. For example, you can use websites: www.zijemesdemenci.cz, www.alzheimer.cz, www.pecujdoma.cz

Still, information from the Internet may be too general for you. With regard to your specific life situation and the condition of your loved one with the illness, consider a personal meeting with a social worker at a specialist counselling centre, preferably one that focuses on home care. You can also visit the social services department of the council where you live. Each social worker will try to provide you with as much information as possible on the subject and refer you to other specialised advisory centres or services. Counselling is provided free of charge. You can take advantage of various social service providers operating in your area. The website of the Register of Social Service Providers in the Czech Republic, which can be found on the website of the Ministry of Labour and Social Affairs, is a good tool for finding a specialist counselling centre or services to help you care for a loved one: www.mpsv.cz/registr-poskytovatelu-sluzeb

Drawing social benefits and allowances necessary to take care of a sick person is one of the areas the workers are well versed in. You can apply for a care allowance and special aids or mobility allowances through the Labour Office.

The **care allowance** is intended for people who, due to long-term poor health, need the help of another person to cope with the basic needs of life. The allowance can be used to pay for the assistance provided either by a close person or by

a registered social service; in the case of people with dementia, this can include outreach services or day centres. If the person with dementia is in a residential social services facility for a long time, the care allowance is payable to the facility.

You can also apply for so-called disability benefits, which include mobility allowance, special aid allowance or a disability card (ZTP, ZTP/P card).

Special Aid allowance, car allowance, disability card (ZTP, ZTP/P).

Mobility allowance is intended for disabled persons (owners of ZTP or ZTP/P disability cards) who need regular transport. The applications are submitted at the Labour Offices.

Compensatory (mobility) aids are prescribed by a general practitioner or neurologist. Most of them are (in full or in part) paid for by the health insurance companies. Such aids include crutches, walkers, wheelchairs, electric reclining beds or aids to facilitate hygiene. These aids are usually prescribed by a GP or a neurologist.

These aids can be obtained from medical supply stores or pharmacies, many can be rented from mobility aid rental shops.

Incontinence aids allowance can be prescribed by a general practitioner, urologist, neurologist or geriatrician for a maximum of 3 months. These aids include pads, fixation pants and absorbent knickers.

Long-term attendance allowance allows people to stay at home to care for a family member whose attending physician at a health care facility providing inpatient care (usually a hospital) has determined that the person's condition requires home daycare after discharge from the hospital. Long-term care 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 is to apply for a **care allowance** under the Social Services Act.

Long-term care allowance must be applied for by the attending physician at a health care facility where the loved one has been hospitalized for at least 7 days, provided that he or she will need long-term care for at least 30 more days.

Legal capacity and limiting it

It is important to remember that every person has the right to decide for himself/herself, even if they may seem wrong from our perspective. Everyone has the right to make free and informed decisions (even wrong ones) within the limits of their mental capacity. Caring for a person with dementia also presents a number of ethical dilemmas.

To be well prepared for the decisions you will have to make on behalf of the person with dementia in the future, it is important to get all the information you need as early in the illness as possible. It is a good idea to talk to the person with the disease, family, friends, doctor and other close people. You can then prepare instructions that faithfully reflect the wishes of the person with dementia in accordance with current laws (e.g. ,previously expressed wishes') and, where appropriate, inform the doctor of the patient's preferences and treatment decisions.

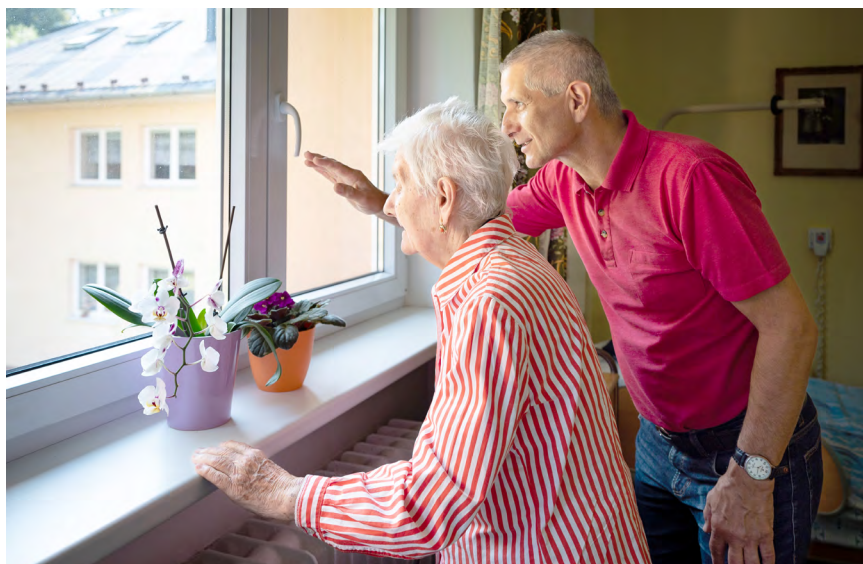


As having dementia brings about problems in independent decision-making, it is a good idea to think about preparing and validating a power of attorney and, sometimes, establishing a guardianship. It is possible to contact any social worker in the municipality, city or borough, depending on where your loved one lives, with these issues.

The Civil Code, in its section 15(2), defines legal capacity as the capacity to act legally, i.e. to acquire rights and to bind oneself to obligations by one's own actions.

If it is in the interest of the person suffering from dementia and the legal conditions are met, the court may decide to limit the person's legal capacity.

It is essential to mention that the legal capacity cannot be revoked (in contrast to 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 that the person is legally incapable of acting. At the same time, it should be added that



it is not possible to limit a person's capacity to commit unlawful acts – such problems must be assessed on a case-by-case basis.

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 must be accompanied also by a medical opinion or a medical report on the condition of the person concerned. If such evidence is not submitted to the court, the court may reject the application.

Mom's condition is slightly deteriorating. She's taking her medication regularly, but she's starting to depend on others for help. We have to remind her of everything. Sometimes she gets lost in the apartment. She doesn't know where the toilet or the bathroom is, where her clothes are, when to eat her food. A few weeks later, her condition deteriorates rapidly. She needs help getting dressed and doing her hygiene.



This is a particularly difficult time for Dad. I realize that as the only daughter, I need to be more involved. Daddy doesn't want to wash Mommy. And put her in diapers. We have some tough decisions to make at home. My kids need me, and my husband needs me. When I'm visiting my parents, I think about what's going on at home, and when I'm home, I think about how Daddy's doing, handling it himself...

... More care is needed – the demands grow

Over the course of the illness, the condition of the person being cared for can change slowly, but it can deteriorate also rapidly. Sudden changes in the person's behaviour can be very challenging for the carer, given the need to adapt quickly to the situation. Areas that may be especially demanding when providing care to a person in need are listed below.

Personal hygiene

Dementia affects a person's ability to take care of their own body (brushing teeth, bathing, grooming and dressing), especially in the advanced stages of the disease.

At the beginning of the disease, it can be assumed that the person being cared for is able to take care of him/herself or only needs supervision to perform these tasks. In the later stages of the illness, however, the need for assistance is already pronounced. Inadequate hygiene and the inability to take care of basic hygiene needs (personal cleanliness, laundry, housekeeping, provision of hygiene products, etc.) in a person with dementia can lead to infections and other health problems. In addition, the patient is aware of the decline in his or her ability to care for him/herself and the loss of dignity – and the loss of dignity necessarily comes as a result of the lack of care. This may also lead to the loss of self-confidence and withdrawal from social activities.

Washing the body and hair is often a significant point of contention or even conflict. It is not unusual for a person

with dementia to neglect hygiene while completely refusing help with the care for their hygiene. The reasons may vary:

- **Shame:** help with bathing or showering may be perceived by the patient as a loss of privacy and he/she is ashamed of it, especially of the need for help from the family carer. It may help if a professional care service is arranged to come and help with hygiene. Sometimes it is easier to undress in front of a professional carer than in front of a relative.
- **Fear of falling:** the patient may be worried about slipping and falling. The bathing process can be made easier by fitting enough handrails in the bathroom for the patient to hold on to and using a non-slip mat or a bath/shower seat.
- **Cold:** elderly individuals often have poorer thermoregulation and the person with dementia may be uncomfortable undressing because they fear they would be cold. However, they are not able to tell us this information. It is, therefore, advisable to preheat the bathroom to a comfortable temperature.
- **Problematic water temperature:** this issue is related to the previous point. A healthy person usually has a significantly wider range of temperature tolerance. What seems fine to us may not suit the sick person. Therefore, it is a good idea to have the patient repeatedly test the water by hand to see if it is not too hot or too cold.
- **Impaired perception of depth and distance:** the patient often finds the bath too deep and may be concerned that he cannot enter it safely and if he does, he may not be able to get out of it. Putting a contrasting pad on the bottom, which the patient can see clearly, may help (the aforementioned wheelchair-accessible shower with a seat is an even better solution).
- **The patient may fear water:** for example, he or she may feel that the bath is too deep and that he or she might drown; lowering the water level or stream may help.

More tips for personal hygiene:

- Let's use the patient's habits to our advantage rather than trying to change them. For example, we can find out at what time of day our loved one likes to bathe or shower.
- It is not necessary to force the sick person to shower or wash every day at any cost. Personal hygiene itself is often physically demanding, so it is enough to use a washcloth or sponge every other day.
- When bathing, use separate washcloths and towels for the face and upper body, and separate ones for the lower body. Towels and washcloths need to be washed regularly.
- When helping a person with dementia with their personal care, we need to maintain communication and continually keep finding out what they would currently prefer. We should respect their decisions. Let them know both verbally and non-verbally that they are safe and that nothing will happen to them.
- Regular personal hygiene can be elevated to a pleasant „spa day“. Such an idea can be much more appealing to the patient. After washing, we can blow-dry their hair, comb it, apply lotion to their skin, or, if they like it and are used to it, offer to put on make-up or make a manicure.

Sleep problems

Difficulty sleeping can be another problem associated with dementia, which may affect the patients themselves, their family and sometimes even people living in the vicinity. People with dementia tend to have trouble falling asleep, may wake up in the middle of the night or too early in the morning, or have a completely reversed circadian rhythm. This disrupts their sleep as well as that of their carers (and, in extreme cases, can put at risk even their carers' health), which usually complicates

the provision of care and sometimes even family relationships. How should we act in these situations to avoid dysregulation of our loved one's circadian rhythm, or possibly to get them back on track?

- Give the day a firm structure: if a routine in which rest has a dedicated place can be established (for example, an hour's sleep after lunch, but no more), the night's rest is often less disturbed.
- The daily routine should include activities that keep your loved one continuously and adequately tired. Adequately is the key word here; if we wear the patient down too early, he or she will fall asleep at, say, 4 p.m. and sleep until 10 p.m., after which we can hardly expect him or her to stay in bed until morning.
- You can introduce certain rituals before going to bed:
 - reduce activities towards the end of the day,
 - make the lighting less intensive,
 - serve a light, low-energy food for dinner,
 - skip stimulant drinks such as tea, coffee or Coke,
 - lemon balm tea, warm milk with honey or a small glass of beer are more suitable evening drinks,
 - difficult topics that could disturb the patient should be left for another day,
 - if the patient is watching TV, the evening program should not contain too dramatic or action-packed scenes,
 - reading the patient's favourite book is much more suitable,
 - play quiet, pleasant music,
- Your loved one may need to go to sleep later (if someone has had just six hours of sleep all their life and suddenly, he/she starts going to bed at 8 pm, they are more likely to wake up in the dark; they might be confused and trying to work out what is happening and where they are).

- Sleep problems can also be associated with depression. If your loved one begins to suffer from insomnia, watch for signs of other symptoms of depression. If you suspect depression, consult a doctor.
- Providing good care is difficult if you are consistently sleep-deprived yourself. Don't be afraid to ask for help and use services such as day care or respite care so you can sleep off the debt from the night at least during the day. Plus, it's also possible that a daily rhythm in a residential care facility might help to properly adjust your loved one's internal clock.

Behavioural changes

Dementia changes the way people behave, think or act. It can be upsetting both for the person with dementia and their family/carers. Although it is difficult, it should not change the way we view the person with the illness or our relationship with him/her. It is important to remember that the changes in behaviour are caused by the illness. You should also remember that many of the symptoms of illness described here may not develop in the person you care for at all.

Some behavioural changes that can occur in dementia can be very distressing for us, carers, and can cause us to feel sad, confused, angry, anxious or even resentful. Such reactions are natural and you should not blame yourself for them, but it is still important to know how to deal with them. Giving in to them can affect our whole relationship with the person we care for. In some cases, they can even lead to the feeling that we can no longer cope.

It is good to remember (and to keep reminding ourselves) that our loved one is not doing this out of malice - similar to a sick young child who keeps us up all night by moaning or weeping. Try to always stay aware of the person's autonomy and rights

and respect his or her individuality. Changes in behaviour are caused by the sick person's altered perception, over which he or she has no control. The patient, therefore, feels anxiety, anger, fear, confusion or frustration, often intensely and for a long time, but is no longer able to show what is bothering him or her except by the behaviour we perceive as ‚problematic‘. You can imagine the following to try to understand them:

„Suddenly, you find yourself in an unfamiliar foreign country. You have no idea how you got here, you don't know what the rules are. You are locked in a house with people who are familiar to you, but you don't know who they really are. These people speak to each other in a completely unfamiliar language and they speak to you as if they expect you to understand them. It is often obvious that they are talking about you, perhaps deciding what they are going to do with you. They make you eat things you have no desire to eat. It is often light at night or dark during the day. At random, activities you don't understand take place and you have to participate; they force you into some of these activities, even if they make you uncomfortable. Sometimes you even feel that they are experimenting on you - something hurts you, but no one helps you, and they make it even worse by their actions.“

Caregiver's reactions

It is very important to understand behavioural changes and to be aware of what precedes and follows them. Sometimes, it is possible to reduce or even prevent certain behaviours. If you pay attention to what precedes or triggers the particular behaviour, you can try to prevent such situations by adapting the environment. Not trying to change the patient's behaviour, but rather to change the environment and the stimuli that affect the patient, is a good way to take. We can liken this to a person in a wheelchair: we cannot change them to do everything

a healthy person can do, but if we adapt the environment appropriately, we can minimise the impact of their disability.

Advice and recommendations:

- Dementia can lead to behavioural changes that can be upsetting or frustrating to themselves as well as to their close ones.
- It is important to identify the triggers of the distressing behaviour and thus understand what may be causing or exacerbating it.
- It is also helpful to observe and realise our own reactions to the changes in the patient's behaviour, how we feel and what we do at such times.
- We can try to calm ourselves down in an upsetting situation: stop, take a deep breath and think about how best to react at the particular moment. Anger will never help us; we need to control our emotions if we want to cope with the situation. Our anger can be actually useful in one way: if we realise how it affects us and how difficult it is to control it, we may find it easier to imagine the experience of the patient who does not understand his or her emotions at all and whose ability to control them is greatly reduced by dementia.
- It is good to try new responses and approaches (examples), as the first choice might not be the best one.
- If you feel unable to manage the situation or understand the patient's actions, do not be afraid to seek professional help - for example, a psychologist or a carers' advice centre.

Eating

An individual's help and quality of life can be affected by the way they eat. The nutritional and fluid intake needs of patients with dementia are similar to those of healthy people of their age. A healthy and tasty diet with the right consistency and sufficient

fluid intake (thickened fluids in the later stages of dementia) are very important for people with dementia (although no special diet is needed).

Over time, it is very likely that a person with dementia living at home will develop problems with preparing meals, using cutlery, remembering to eat and drink, chewing and swallowing. All of this can lead to malnutrition and dehydration, which increases the risk of weight loss, delirium and acute confusion. As a result, the demands on the amount of care provided by the family caregiver are increased as supporting the elderly person with dementia at mealtimes is important but time-consuming.

The person with dementia sometimes experiences rapid weight loss (wasting, cachexia) without any obvious physical cause. It is advisable to discuss this with your loved one's doctor.

If the person with dementia does not eat regularly, use every spare moment to serve food. If he or she has a habit of walking around the flat, you can set up „food stations“ by placing plates



of food that can be picked up (e.g. sliced apples, biscuits, etc.) along the favourite route. Sick people often take.

On the other hand, regularity of meals may help your loved one in maintaining time awareness and, in addition, to physically and psychologically better prepare for the meal and look forward to it.

Try various foods. Find out what the patients liked when they were young. Approach a nutritional therapist and ask him or her to work with you and your loved one to design a suitable diet.

If you are not living in the same household with the patient, keep an eye on the food in the fridge: if the food stock is not diminishing or, vice versa, is dwindling too quickly, you need to intervene. Note that even if you share a household with a person with dementia, it does not mean that they are unable to judge (at least from a certain stage) if they are hungry. The carer should also keep track of the expiry date of food that the person with dementia has in their home.

The delivery of lunches, e.g. by a care service, is one way of monitoring and ensuring the regularity of meals. This service may involve helping to serve lunch; experienced carers can create a pleasant atmosphere and the person often perceives the lunch an important social event.

Swallowing disorders

As dementia progresses, dysphagia (difficulty swallowing) often occurs, especially with regard to certain types of food. This results in spitting out chewed pieces of food or holding food in the mouth. It is not uncommon for the elderly with dementia to put too much food in their mouths and not swallow it, which creates a risk of choking. Recommendations for relieving difficulty swallowing:

- serve soft foods with a smooth consistency (eliminate dry, hard foods that require a lot of chewing),
- use sauces in the meals to help soften food,
- offer small sips of liquid to wash down individual bites,
- be careful with foods containing small pieces (rice, lentils), which may be aspirated and the patient may start choking. Do not leave the patient alone at such meals and, if possible, completely avoid these foods for safety reasons,
- avoid crumbly foods (biscuits), fruit with skin or pits,
- encourage the patient verbally to swallow individual bites,
- check the mouth after eating (to verify if any food is left in the mouth),
- ensure that the patient remains seated for a short while after eating (prevention of aspiration of an unswallowed bite),
- cut all food into small pieces before the patient starts eating,
- encourage the person to eat more slowly and to chew and swallow each bite,
- use smaller cutlery (teaspoon, dessert fork).

Impaired independence at mealtimes

As the disease progresses, people with dementia may find it difficult to eat and drink independently. Dementia causes difficulties with coordination and remembering procedures related to eating and drinking. These difficulties cause an increase in the time needed for eating. In the early and middle stages of the disease, the person with dementia should be encouraged and supported to stay at least partially independent for as long as possible (use the retained abilities as much as possible, use appropriate aids, but also be ready to help if needed). Recommendations for supporting independence at meal times:

- Eat together - looking at another eating person can help the patients recall how to use a fork or a spoon, even though they could not remember it themselves,
- use 'finger food' (food in the hand, which the senior takes between his or her fingers and does not need cutlery). The portion size should be just about one or two bites that are easy to scoop up (e.g. fish fingers, apple pieces, fried cauliflower, meatballs). Food prepared in this way allows the person with dementia to feel that they are still independent and can eat alone, even if unable to use the cutlery, thus maintaining dignity and control at mealtimes.
- find out if the vision of the elderly with dementia is all right
- ensure good lighting in the room where food is served,
- point out where cutlery and plates are placed on the table,
- prepare the food in a colourful and attractive-looking way,
- describe the food you are offering to the person,
- don't use tableware and tablecloths with patterns (they distract from the food),
- use colour contrast to make food more visible - put colourful foods on white plates (spinach, tomato sauce, salmon), and, vice versa, bright foods on coloured plates (dill sauce, mashed potatoes, white fish)
- choose tableware that makes eating easier (bowl instead of a plate; plate with a raised rim; spoon with a large handle instead of knife and fork).

Problems with fluid intake

People with dementia often suffer from insufficient fluid intake because they lose their ability to be thirsty as well as to drink independently. Recommendations for ensuring sufficient fluid intake:

- encourage the patient to take in small amounts of fluid more frequently during the day,
- ensure that they have a cup or bottle filled with water at hand,
- if the person refuses to drink water, try to offer other sources of liquids (soup, juices, „watery“ fruit such as seedless watermelon).

Safe home environment

Dementia has a significant impact on the everyday life of the elderly, including their ability to continue living in their home environment. Memory problems or difficulty recognising objects around them can lead to frustration and become a cause of injury in the home environment. However, as the disease progresses, the person may become unaware of the danger. Therefore, creating a safe home environment that prevents dangerous situations from arising and helps to maximise the independence of the person with dementia



for as long as possible is important. The home environment has a significant positive impact on the person with dementia, but an unsafe environment may affect them negatively. A familiar environment promotes mental well-being and encourages independence. Safety and security are important aspects of the home environment.

General tips for a safe home environment

- always store potentially dangerous items (medications, matches, sharp objects, small appliances and tools) in a locked cabinet;
- cleaning and laundry products (gels, powders, capsules, pastes) should be kept out of sight and reach of the elderly to prevent accidental ingestion of harmful chemicals;
- all areas of the home environment should be sufficiently lighted (rooms, halls, terrace). Using white paint on the walls is beneficial as it does not absorb light. Prefer curtains without patterns, as they let the light in evenly. Large patterns on curtains can create moving shadows that make the patient uncomfortable. At night, on the other hand, curtains or screens should be drawn so that the outdoor light does not disturb the person;
- remove objects that increase the risk of tripping and falling (small rugs, loose extension cords);
- secure any large pieces of furniture that the patient could knock over (bookcases, shelves, cabinets) to the wall;
- remove rocking chairs - their stability is low and they are difficult for the patient to get up from;
- reduce the risk of falling when getting up from a chair - use chairs and armchairs with arms that provide support when changing position from sitting to standing;
- make door glazing clearly visible - put on stickers at eye level;

- remove locks on the interior doors so that the patient cannot lock himself/herself in;
- ensure that the space is wide enough for safe and comfortable movement around the flat (take the width of the walker or wheelchair into account, if applicable);
- use smoke, carbon monoxide, and water level detectors in the apartment;
- set the maximum water temperature to prevent scalding;
- limit or remove any elevated surfaces (stairs, thresholds, different flooring types) as elderly with dementia often shuffle their feet when walking and could trip and fall. If this is not possible for structural reasons, highlight these projections with a contrasting colour;
- use protective caps on unused electrical sockets;
- ensure the telephone and doorbell are sufficiently loud;
- secure doors with stairs behind them (entrance to the cellar or an attic) by locking or disguising them. If other family members must use them, put a barrier in front of the door;



- have spare keys ready in case the person with dementia loses or misplaces theirs and cannot find them;
- ensure the home is secure (gas, water, electricity) - maximum water temperature, sensor reporting the opening of the front door, locking the front door;
- disguise the doors or cabinets you do not want the person to open;
- remove high thresholds, skirting boards, loose carpets, all-glass doors, mirrors.
- secure the electric sockets and drawers, opening/closing the windows (e.g. install window locks).
- apply sensory cues - scented cushions, aromatherapy, touch and hearing, variety of materials, soothing sounds - ticking clocks, music, audiobooks, make the person's favourite place as cosy as possible.

The care is becoming increasingly difficult. I try to go to my parents every other day, but I see it's not enough anyway. Blood sugar and blood pressure of Dad, who will turn 79 this summer, has increased. Even though the outreach carer comes twice a day, I can see it's too much for Dad. We're starting to consider putting Mom in a nursing home. It's very difficult for us, especially for Dad who feels like he has failed.



Ethical dilemmas in care

When caring for a loved one with dementia, the need to „recharge our batteries“ literally becomes a drug we cannot do without. We don't have to look for anything complicated, even small things like a walk in nature or a coffee and a chat with a friend often help. It's not always easy, as the care often takes a lot (if not all) of your time. That's why it's essential to find someone to regularly cover for you when caring for a loved one with a disease, so you can get some time off.

Former carers' recommendations to current carers

- Live your life too. Don't abandon your interests.
- Collect information on the disease and possible manifestations.
- Accept that you are caring.
- Do not take the behaviour of the sick person personally.
- Do not blame yourself for the patient's hospitalisation.
- Save your strength
- Accept the fact that this is an illness ending in death.
- Don't be alone, look for help from loved ones and professionals.

10 symptoms of caregiver's stress

- denial (the diagnosis is not correct),
- anger (that no cure is available),
- separation from friends, limiting time for hobbies,
- fear (what the next day brings, whether the carer can handle it),
- depression,
- exhaustion,
- sleeplessness (waking at night from fear of the patient falling),
- irritability,
- inability to concentrate = difficulty in coping with normal activities,
- health problems (physical and mental)

Schema 2: 10 symptoms of caregiver's stress



10 steps to coping with the stress of caring

- get a diagnosis as soon as possible,
- find out where you can get help,
- get as much information about the illness as possible,
- seek help (you don't have to manage everything on your own),
- take care of yourself!!! (walks, cinema, theatre),
- learn to manage your stress (relax, consult with a doctor),
- accept changes,
- plan all money-related and legal matters (if possible also with the sick person and the rest of the family; you may consult a lawyer - you will be calmer later),
- think realistically (focus on the now, on every day, on nice moments...).

Schema 3: 10 steps to coping with carer's stress

Self-help groups

People in the role of long-term carers often find themselves at the limits of their mental and physical strengths. The everyday full commitment to the other person and caring for their needs is understandably very demanding and exhausting. To give the best of oneself to the sick person, we should also think about our own needs. Besides resting, many people find it helpful to be able to talk openly about their worries, feelings of helplessness, and isolation from the outside world with those who fully understand them because they are or were going through the same or a very similar experience. Mutual respect and understanding, as well as a wealth of ideas and

new suggestions shared in self-help group meetings, provide invaluable support and give people the strength and courage to continue caring.

A self-help group works on the principle of mutual sharing and cooperation, offering insights into the experience of caring for the person and for oneself, and providing support to several clients at the same time. It is an open (not psychotherapeutic) group, in which the service is provided by a professional (facilitator) leading the group, an organiser, as well as by the participants in the group during mutual sharing.

The group also helps to address a wide range of issues related to the daily life of the person with dementia throughout all stages of the disease, addressing issues of access, communication, family relationships and other areas.

Mom has been in a nursing home for almost a year now. Every other day, someone comes to visit her. I try to help by at least driving her to the doctor. Dad sold his car because his sight has grown worse. Mom hardly recognizes us anymore. At least I think so. She sleeps most of the day. She can barely swallow at all, but after talking to the doctor, we refuse to feed her through a probe.

We want her to live out her last days as peacefully as possible. And I hope we've done that. Mom died peacefully one autumn day at the age of 78. We're grateful to have been with her in her final hours.



Caring for a person with dementia at the end of life

Residential care facilities

If you decide to place your loved one in a residential care facility, make peace with it. Don't blame yourself. There are many good quality social services available now.

When choosing a nursing home, think about the fact that support of the family should take place at all levels and should be one of the priorities for care in the nursing home. At the beginning (during the first meeting and the first inspection of the patient's home before admission to the facility), the family should meet with compassion for their difficult situation, feel appreciated for their care to date, and be given sufficient information about where their loved one is being admitted to, what lies ahead and what is expected of the family.

The family should be seen as a partner, as a participant in the care, as an important source of information about the client, as one who can be helpful in individual planning, in sharing



the patient's life story, participate in social events and accompany the patient there, bring small treats, such as sweets, and food supplements for the loved one, bring grandchildren, etc. Cooperation with the family is an essential part of the individualised care and quality of life of each client of the residential service.

The family should be a welcome (and invited) guest in the nursing home, should be able to find spaces for intimate meetings with a loved one, facilities for sitting down for coffee or for visiting with children (children need a place to play). They should also meet helpful and knowledgeable staff who can patiently answer the family's questions, respond to their concerns and fears, and offer advice when the family needs it. The family is then part of the whole process of care, from admission to the end of care, which most often means the death of the loved one. The family participates in the life of the institution and helps create the character of the institution through its attitude, involvement in care and relationships. Both the family and the client enjoy respect and dignity, and the family is supported in the terminal stages and in the death of the loved one (as part of palliative care). In this way, the service provider can prevent the well-known phenomenon of a gradual decline in the number of visits and contacts between the family and the person living in the institution as well as the various manifestations of ill-treatment of family members by their relatives and their complaints against the staff.

The home environment

If the carer wishes to continue to care for their loved one in their home environment, several options can be used - particularly outreach social services and specialist support provided in the home environment.

In the case of a progressive increase in the need for care, it is possible to find **expert advice** in specialised **counselling**

to maintain the standard of care when you are in an emergency situation such as sudden illness or injury.

The caregiver can prepare an emergency care plan on the website www.pecujdoma.cz

Source: <https://www.pecujdoma.cz/nase-sluzby/nouzovy-plan-pece/>



Jste pečující a obáváte se situace, že se náhle nebudete moci starat o své blízké?

Využijte Nouzový plán péče

Nouzový plán umožní **zastoupit vás v péči**, když se ocitnete v nouzové situaci jako je náhlé onemocnění, hospitalizace či úraz. Tato novinka vznikla v Irsku jako reakce na pandemii koronaviru a obavy pečujících a byla ve **spolupráci s odborníky přizpůsobena českým podmínkám**.

Jsem pečující a je na mně závislá další osoba.

JAN NOVÁK 012345

Zavolejte prosím bezplatnou linku Pečuj doma
800 915 915 nebo tísňovou linku 112.

Potřebujete se dozvědět více? Nebojte se na nás obrátit...

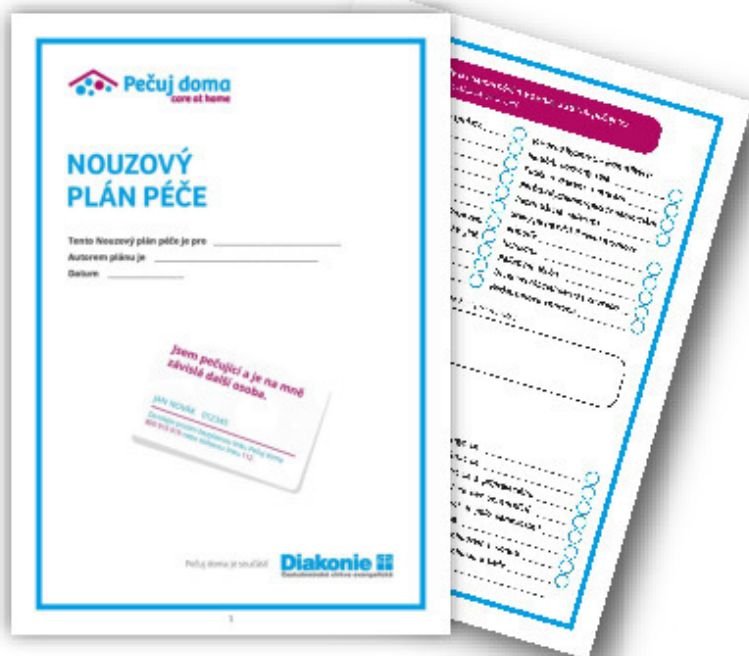
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bezplatná poradenská linka pro pečující, denně od 9 do 20 h.

poradna@pecujdoma.cz • www.pecujdoma.cz

„Nouzový plán péče využiji i jako praktická lékařka, při výjezdech je užitečné, že budu mít k dispozici všechny údaje o daném člověku.“

MUDr. Eva Kasalická, praktická lékařka Křivo klát, Sdružení praktických lékařů ČR



„V Prachaticích se připojujeme k Nouzovému plánu péče, protože z praxe víme, že pečující se často bojí právě toho, že se o jejich blízké nebude mít kdo postarat.“

Hana Rabenhauptová, referentka pro sa mos právu a lo munitní plánování,
MěÚ Prachatce

Nouzový plán péče už máte a co teď? Od počívejte a užívejte si vědomí, že pokud se něco přihodí, jste připraveni — máte nouzový plán péče.

Diakonie 
Ceskoslovenská církev evangelická

Mum left. She left a void that no one could ever fill. That's for sure. I keep wondering, did we make it? Did I make it? Could I have done better, is there something we should have/ could have done but didn't?

Questions without answers.

Dad and I go to her grave regularly. I know his loss is much greater than mine. He lost his life partner. I can see in him how the last few years, the intense care for his wife, have marked him, how he's aged. I celebrated my round anniversary in August. When my dad was giving me his congratulations, he hugged me and held me in his arms for a long time. „Thanks for everything, I couldn't have done it without you.“ And I realized again that all those years that were not easy had a purpose. It wasn't a waste of time. On the contrary. I want to believe that even though my mom no longer perceived and maybe didn't even know who was taking care of her and why - if she could, she would have hugged my dad and me and thanked us too. Now it's time to move on.



Conclusion

Support, sharing, understanding

Any of us can find ourselves suddenly in the role of caring for a loved one. Caring for another person brings many challenges and difficult moments. We hope that the brochure you hold in your hands has provided you with helpful information for your journey as a caregiver. It is understandable that in your role, you often feel exhausted and at the end of your rope. It is important for the carers to realise that the person with dementia they are caring for is not in control of their behaviour. It is important to try to be patient, while, on the other hand, not blaming oneself for any failures. We are only human.

This brochure aimed to support you, caregivers, in your demanding task. We hope that its contents will help you understand the issues of caring for a person with dementia in the home environment and save you time that you will be able to spend with your loved ones or just keep it for yourself.

The care you give to your loved one makes immense sense. Believe me, if your loved one could, he or she would certainly thank you for it.

„I will love the light because it shows me the way, but I will also endure the darkness because it shows me the stars.“

Og Mandino



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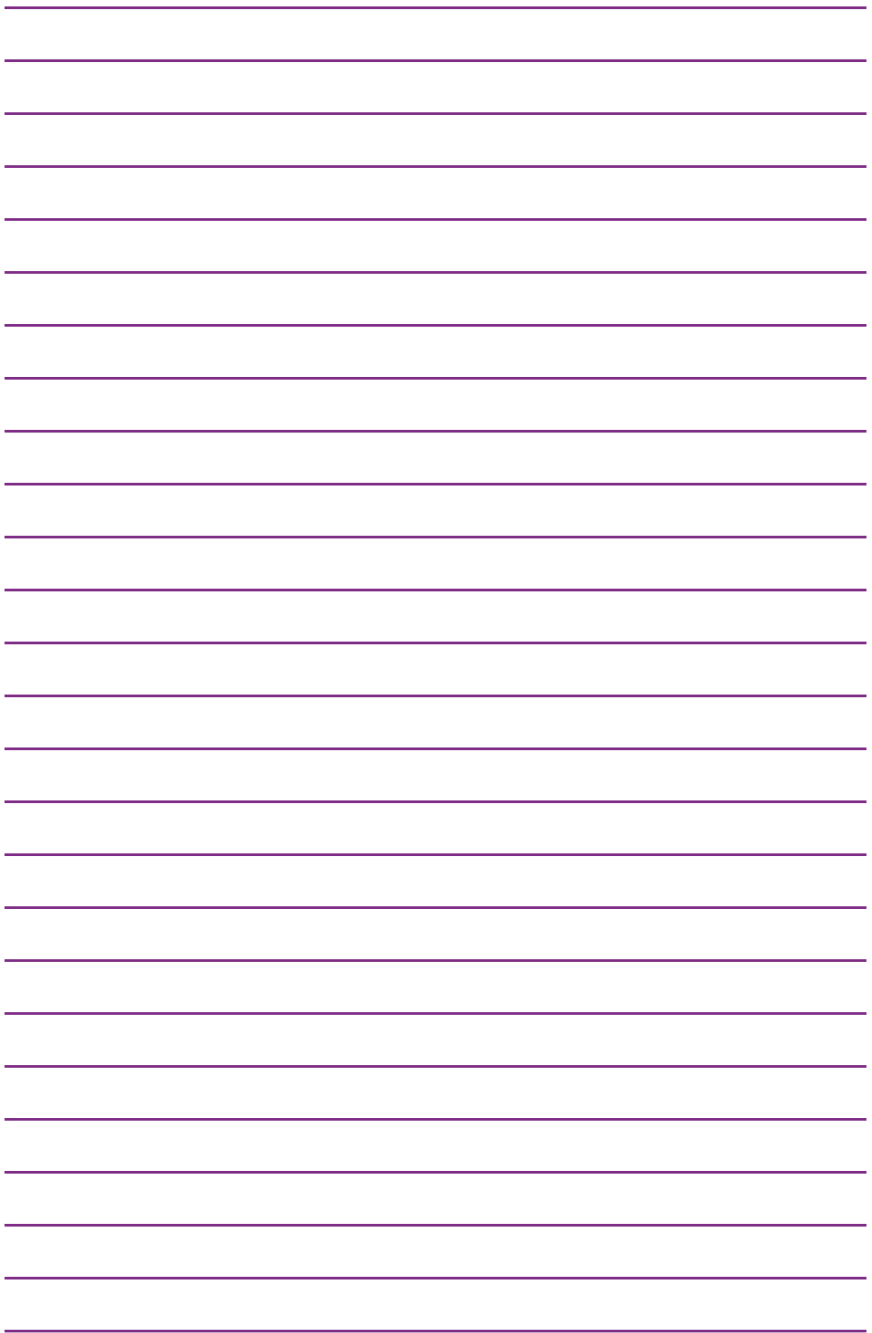
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Together in caring for a person with dementia

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