

A close-up portrait of an elderly woman with short, wavy brown hair. She has a gentle smile and her hand is resting under her chin. She is wearing a dark blue, textured sweater. The background is softly blurred, showing hints of an indoor setting with light coming from a window on the left.

volkshilfe.

UNDERSTANDING DEMENTIA

UNDER- STANDING DEMENTIA

WE WON'T LET YOU DOWN.

In this brochure, our aim is to explain the different forms of dementia and the various courses of the disease in an easily understandable way. Information from the fields of medicine, research, treatment and care is designed to help those affected and their families to acquire a better understanding of the disease and thus enable them to organise their time together in a meaningful way.

**Yours sincerely,
Volkshilfe**

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WHAT IS DEMENTIA?

As opposed to a heart attack, dementia creeps almost unnoticed. At the beginning, minor mishaps occur: an appointment is forgotten, a key gets lost, a room is entered and the reason why forgotten. The onset of the disease is easily overlooked by those affected and their relatives because minor uncertainties in the ability to remember occur occasionally in everyone. To complicate matters, the first symptoms can vary enormously. The main focus is on forgetfulness, but sometimes the first symptoms can also be uncertainty, fear or a change in behaviour. For this reason, it is all the more important to be alert to any changes in behaviour and memory and to any changes in the daily routine of relatives, friends and oneself.

YOU'RE NOT ALONE

It is often assumed that forgetfulness is always part of old age. This is popularly referred to as senility. Neither the first assumption nor the popular reference is correct. A deterioration in mental capacity is not a normal process in elderly people but rather a disease that has to be treated.

POSSIBLE CAUSES OF DEMENTIA

Dementia diseases are always split up into primary and secondary forms. Whilst in primary forms, dementia itself constitutes the disease, secondary forms are the consequences of other underlying disorders, e.g., metabolic diseases, vitamin deficiencies and chronic symptoms of poisoning by alcohol or medicines. The causes of primary forms of dementia have not (yet) been clarified conclusively. However, research has revealed important findings about the course, risk factors and various types of dementia.

The nerve cells of the brain are constantly exchanging information by means of electrical impulses. The latter travel along the nerve fibres like in an electric cable. Information is passed on from one nerve cell to the next by converting the electrical impulses to chemical ones. Conversion is performed by neurotransmitters in the synapses (small protrusions at the end of the nerve fibre). Different neurotransmitters are responsible for different tasks in the brain.

The two most important neurotransmitters for learning processes are glutamate and acetylcholine. These are also largely responsible for remembering, thinking, learning and spatial orientation. For reasons that are still unknown, a filamentous, insoluble protein (amyloid) is deposited outside and inside those nerve cells. One consequence of such pathogenic protein deposits in and around the nerve cells is the death of acetylcholine-producing nerve cells.

DIFFERENT FORMS OF DEMENTIA

Dementia is the generic term for medical conditions that involve loss of mental functions, such as thinking, remembering and orientation. Everyday activities can no longer be performed by patients on their own.

PRIMARY FORMS OF DEMENTIA

Dementia diseases can occur as primary forms. They are dementia diseases that damage brain cells without any apparent cause.

Alzheimer’s dementia

Alzheimer’s disease is the most common form of dementia disease (approx. 60%–65%). Here, cerebral nerve cells in the brain die over a period of many years, especially in the areas of memory, motivation and feelings. The characteristics of Alzheimer’s dementia are the gradual onset of the disease and a gradual deterioration of memory performance. In the advanced stage, there are also mood swings, aggression and depression. In addition, people affected lose their sense of time and place and are increasingly dependent on support.

Lewy body/Parkinson's dementia

In the second most common form of dementia, parts of the brain are affected by deposits of protein bodies (Lewy bodies). The characteristics are small-step gait, stooped posture and lack of motivation. Sharp fluctuations in memory performance and visual hallucinations can also occur.

Vascular (vessel-related) dementia

In vascular dementia, vascular changes bring about a reduction in nutrient and oxygen supply to the brain, which then leads to a gradual death of nerve tissue. The symptoms of vascular dementia resemble those of Alzheimer’s dementia. Owing to an inadequate supply of blood to nerve tissue in the brain, a feeling of numbness or signs of paralysis can also occur.

Frontotemporal dementia (Pick’s disease)

In frontotemporal dementia (FTD), nerve cells in the forehead and temple area of the brain die (i.e., in the frontal and temporal lobes). Changes in personality and interpersonal behaviour soon become evident in the early stage of the disease. People with FTD lose their motivation to do things and become increasingly maladjusted and distanced. Furthermore, they begin to pay less attention to personal hygiene.

SECONDARY FORMS OF DEMENTIA

Secondary forms consist of dementias diseases where the mental change is the result of a different organic disease, e.g., a brain injury or a cardiovascular disease. Pharmaceutical substances and poisons, such as alcohol, can also lead to dementia. If the underlying disorder is treated effectively or if poisonous substances are no longer affecting the brain, mental capacity is usually normalised (resumed). If, on the other hand, the sensitive nerve cells were exposed to the damaging effect for too long, permanent damage can occur.

Wernicke–Korsakoff syndrome (“alcohol-related dementia”)

Approx. 5% of alcoholics sustain permanent brain damage as a result of chronic alcohol abuse. Symptoms arise such as memory disorders, disorientation, limited ability to plan and act, impaired judgement and serious personality changes.

DEMENTIA FACTS AND FIGURES

The word dementia comes from the Latin “demens”, which when translated means “out of one’s mind”. That is misleading. After all, a person’s “mind” still exists during the disease; it merely changes occasionally. When we use the term dementia in this context, we do it consciously in order to discuss a disease in a matter-of-fact and confident manner that is often kept secret and marginalised.

Experts estimate that in Austria there are between 100,000 and 147,000 individuals living with a form of dementia. According to projections, that figure will double by the year 2050—accounting for more than 3 percent of the population. Even now, dementia is already the most frequent reason for relocating to an old people’s home/ nursing home. In the case of individuals aged between 65 and 69, the proportion of persons affected is 1.3 percent of the population.

However, as age increases, the incidence rate increases rapidly. In people over the age of 90, the rate is nearly 41 percent. Alzheimer’s dementia accounts for 60–80 percent so it is the most frequent form of dementia diseases.

AGE-DEPENDENT INCIDENCE OF DEMENTIA

Austria 2018						
Age	Total population	Men	Men with dementia	Women	Women with de- mentia	Total number of people with dementia
30–59	3,785,059	1,897,779	3,036	1,887,280	1,699	4,735
60–64	523,556	253,644	507	269,912	2,429	2,936
65–69	448,191	211,851	2,345	236,340	3,546	5,891
70–74	380,051	173,824	5,384	206,227	7,017	12,402
75–79	383,384	168,992	11,791	214,392	19,138	30,929
80–84	210,513	85,112	9,079	125,401	16,368	25,447
85–89	144,461	51,017	8,312	93,444	23,221	31,533
90+	80,392	20,484	6,083	59,908	26,844	32,927
Population 30-90+	5.955.607	2.862.703	46.537	3.092.904	100.263	146.801
Total population	8,822,267	% of total population 1.66				

Source: Alzheimer Europe Association, 2018

HOW IS DEMENTIA RECOGNISED?



Even prior to diagnosis, people often have the feeling that something is not quite right. If a suspicion of dementia proves to be correct, an early diagnosis can help to ensure that the medical condition will progress positively. Although dementia is still incurable, its course can be considerably alleviated by treatment with medicines or activating therapeutic measures.

If you have the feeling that you or a relative might have symptoms of dementia, don't hesitate to consult a doctor.

Here are some of the reasons why an early diagnosis is important:

- secondary forms of dementia can be cured;
- therapeutic measures can be taken early that maintain everyday abilities for a longer period and improve the quality of life;
- more time is available for planning the future;
- other diseases that manifest similar symptoms to those of dementia can also be recognised;
- more activating measures (e.g., attending a day centre) are possible to ensure social participation.

The diagnosis may be scary at the beginning, but it can also provide relief because an answer has been found and it is now possible to make decisions on the basis of new knowledge in order to maintain the quality of life for as long as possible.

DIAGNOSIS

The family doctor or specialist will have a detailed discussion with the person affected. Interviewing the relatives is also important when diagnosing dementia.

The dementia test consists of scientifically proven, standardised examination procedures with which brain performance can be assessed. The individual tests cover temporal, spatial and personal orientation as well as checks concerning memory, ability to express oneself, logical thinking and simple activities.

On our website, you will find a list of specialised diagnosis centres and outpatient memory clinics in your vicinity: www.demenz-hilfe.at and at the dementia service consultants in your state.

COURSE OF THE DISEASE



The course of dementia varies enormously from person to person. How it develops depends on many personal factors, e.g., general state of health, personality, physical condition and lifestyle. Dementia can always be split up into three stages: early, middle and late.

At the beginning, those affected often notice that something is not quite right and their abilities are gradually failing. Many people attempt to conceal their limitations. In many cases, they succeed in maintaining a façade for a lengthy period, especially vis-à-vis strangers.

EARLY STAGE

The early stage mainly involves memory and orientation problems.

MIDDLE STAGE

The signs of the early stage gradually increase and reach a level where living independently becomes difficult.

LATE STAGE

This phase in particular is quite difficult for everyone involved. Persons affected often respond in an irritable or aggressive manner if someone—as they see it—wants to confuse them with false information, and they become more and more disoriented.

EARLY STAGE

In many individuals, dementia initially begins with a few symptoms that are still irregular at the onset. Even though persons affected notice changes, they are still able to adapt to them and thus mask their symptoms, for example, by bridging their memory gaps with written reminders.

In the course of time, however, the changes also become evident for relatives, friends and acquaintances. Those affected become increasingly “scatterbrained”, misplace important things, forget information, have difficulty following discussions or seem to increasingly lose interest in social interactions. In some cases, those affected also appear to become increasingly irritable or aggressive for no apparent reason.

At this point, a doctor should be consulted in order to clarify the causes and diagnose dementia if appropriate. After all, the symptoms of apparent dementia can also have quite different causes, e.g., depression or a thyroid gland disorder.

SIGNS IN THE EARLY STAGE

- Difficulties speaking (finding the right words, ability to express oneself);
- Significant impairment of memory, especially short-term memory;
- Problems with sense of time;
- Orientation problems (getting lost in familiar surroundings);
- Difficulties making decisions;
- Lack of initiative or motivation;
- Signs of depression or aggression;
- Declining interest in hobbies or everyday activities.

MIDDLE STAGE

At the beginning of the disease, the person’s short-term memory tends to fade. People with dementia can no longer correctly recall what was for breakfast a few hours before. However, those affected still remember scenes from the past quite accurately, e.g., experiences from the war, their own wedding, scenes from life with their children, etc. As dementia progresses, the long-term memory also fades more and more.

Even small mental challenges are regarded by those affected as excessive demands. Because newly perceived information can no longer be grasped properly, contact with others becomes increasingly difficult. In conversation, people with dementia can scarcely refer to the topics at hand.

Orientation becomes increasingly difficult, sometimes even in their own home. However, at the same time, there may be an increased need for mobility. This aspect makes living independently more difficult, and those affected are increasingly dependent on assistance. In addition, their day–night rhythm may be disrupted, and in some cases, this may be accompanied by delusions and hallucinations. The individuals see things or people that are not present, and they soon feel as though they are not being taken seriously when they express their views.

The middle stage is characterised by the need for more and more assistance. Behavioural problems increase, whilst unrest, running away, rebellion, etc., now tend to occur more frequently. In the middle stage, it is no longer possible for people with dementia to live their lives independently; they require assistance and instructions for everyday activities and when it comes to structuring their daily routine.

SIGNS IN THE MIDDLE STAGE

Persons affected already have difficulties with everyday activities and

- can become very forgetful, especially when events and names from the immediate past are involved;
- are no longer able to live on their own and can no longer cook, clean or shop for themselves
- need support and assistance with dressing, washing and going to the toilet
- suffer from the so-called “urge to wander around” as well as other behavioural disorders and get lost in their own home or in familiar surroundings;
- suffer from hallucinations and delusions.

LATE STAGE

As the disease progresses, those affected are entirely dependent on support and care. Language is increasingly forgotten and speaking involves considerable effort, even physically. Chewing, swallowing and breathing also become difficult. Loss of bladder and bowel control.

In the final phase of the disease, those affected are in the so-called embryonic stage. They are bedridden and require palliative care. This phase of the disease is especially challenging for everyone involved. At this stage, tremendous understanding and strength are required, especially on the part of caring relatives.

SIGNS IN THE LATE STAGE

- Everyday abilities disappear. Independent washing, dressing and the use of knife and fork are no longer possible;
- Eating and drinking become more difficult. In the case of eating and drinking, it may happen that food or drinks are no longer recognised, the mouth is not opened, and chewing and swallowing prove to be difficult;
- Loss of bladder and bowel control;
- Familiar persons and objects are no longer recognised;
- Increasing immobility;
- Loss of language, where neither words nor sentences can be formed correctly.

PROPHYLAXIS AND PREVENTION

Dementia is widespread in Austria on account of the increasing life expectancy. Although it has not been possible to find sustainable methods of curing the disease, studies nevertheless confirm that preventive measures reduce the risk of dementia.

Healthy diet

Those who would like to keep themselves fit, not only physically but also mentally, should eat a healthy, balanced diet. Specific nutrients, such as vitamin E and vitamin B6, stimulate brain activity and have a preventive effect in counteracting dementia. Vitamin E boosts cognition and can be found in vegetable oils, nuts, legumes and green vegetables. Increased levels of vitamin B6 can be found in animal and vegetable foods. Because the human body is 80% water, it is also important to drink adequate quantities of water. The recommendation is 2 litres of water per day.

Regular exercise

Sporting activities and regular exercise not only keep the circulation going but also promote health. Going on long walks, climbing stairs and gardening should be integrated into everyday routine for as long as possible.

Mental activity

Crosswords, sudokus and numerous other memory exercises train the grey matter of the brain and ensure mental fitness. In addition, reading the newspaper, following the news and contending with new things and the present moment also increase brain activity. Active participation in family life and discussions also constitute valuable memory training exercises.

Active social life

To protect against social withdrawal and social isolation, it is advisable to maintain one's circle of friends and acquaintances. Even if friendships are lost as age increases, active communication and open-mindedness can help to create new acquaintances that are enriching and enjoyable.

POSSIBLE TYPES OF TREATMENT



Dementia diseases are not curable, but they can be treated. Every type of treatment must always be made to suit individual requirements. That is the only way treatment successes can be achieved. There are medicinal and non-medicinal treatments that can help to maintain mental and physical abilities as well as the quality and happiness of a person suffering from dementia for as long as possible.

THE RESULT OF THIS CAN MEAN THAT

- progression of the disease is slowed down;
- those affected can live in their home environment for as long as possible;
- self-esteem is enhanced, and symptoms are reduced;
- the burden for caring relatives is reduced.

From the very beginning, it is necessary for caring relatives to also be integrated into the treatment. The role of relatives becomes increasingly important the more those affected become less able to provide information during the course of the disease.

There are medicinal and non-medicinal treatments. Discuss various treatment options with the attending doctor.

WORKING WITH THE BODY AND SOUL

These procedures require special training, but they also offer relatives numerous ideas that can be used in everyday care. This applies to music and physical exercise, for example. Knowledge of the abilities, interests and preferences of those affected helps to choose what is suitable for each individual case. It should be enjoyable for the persons affected.

BIOGRAPHICAL APPROACH

The personal life story offers many different opportunities for bringing back memories and holding conversations. This is a good way of activating the individual's memory.

"Biography" means "life description or life story". It expresses a person's individual maturing process, which is characterised by various influences (e.g., family, occupation and social environment). In many people with dementia, the new memory is severely impaired, whilst they are still quite able to recall events that took place in the distant past: They might not know what they ate an hour ago, but they do remember the names of schoolmates and can sing along to pop songs from their youth.

When caring for people who are suffering from dementia, it is useful to repeatedly bring up the person's life story. Memories and conversations promote mental capacity and maintain the individual's personality. Experts refer to this as the "Biographical Approach".

Incentives for life story memories

There are numerous ways of bringing back memories. The stages of life offer many points of reference: What was it like at school, during educational training or at the sports club? What was it like when the children were small and the house was being built? Old photos, films and music of the time, postcards of holiday travels, personal items, articles of clothing, favourite dishes from childhood, festivities and sporting events are ideal.

Extracting positive life moments from memories

When dealing with the life story and memories, the focus should be on positive experiences. When looking at a family photo, it isn't appropriate to ask who is pictured. Patience is often required before the first memories are recalled.

Addressing individual needs

For professional biography work, it is essential to allow time and space (listen and understand) and thus build confidence. It is important to monitor how a person with dementia responds to events of his or her life story. Many people enjoy recalling stories from the past. Others react indifferently or disapprovingly and prefer to occupy themselves with the present. This should be respected.

Naturally, in any life story there also unpleasant and sad or tragic experiences. It is important to handle these memories with extreme caution.

Under certain circumstances, it may be necessary to enlist the help of therapists or psychologists to process those experiences.

ERGOTHERAPY

The aim of ergotherapy is to promote the independence of patients in all aspects of life. Ergotherapy, which was previously also referred to as occupational therapy, can, at the early stage of dementia, promote the everyday activities of those affected (e.g., independent dressing or bathing). The aim is to use activities to enable the greatest ability to function in everyday situations and to enjoy a quality of life and social participation.

The methods used employ special training materials, craft and design techniques and practical life exercises. In addition, there are many different exercise programmes, and work is performed with various materials.

As the disease progresses, therapy focuses on enhancing body awareness and physical exercise.

GARDEN THERAPY

Garden therapy uses nature in order to enhance the person's psychological and physical well-being.

Even 250 years ago, forward-looking physicians developed the idea of occupying mentally ill people in a meaningful way. Garden design for the living environment was of particular therapeutic importance. However, gardening and farming disappeared from many therapeutic institutions in the post-war years. Only since the beginning of the 1980s has the garden been rediscovered as a space for therapy.

Therapy gardens can look quite different

Gardens for senior citizens require sufficient resting areas so that they can also walk round the garden. Like gardens suitable for the disabled, they should be designed as barrier-free as possible. The needs of people suffering from dementia call for differentiated environment planning that compensates for as many disease-related deficits as possible, corrects environment-related degradation processes and enhances the psychological well-being those suffering from dementia.

Decorative planted areas, water elements, stone objects or romantic arbours stimulate the senses, offer a place to retreat, bring back memories and can thus provide bridging functions to the past.

Many of these elements can also be integrated into a private garden. In this way, elderly people can still derive pleasure from their garden they have grown fond of over the decades.

Appealing to all the senses

Garden therapy focuses not only on organic diseases (e.g., disabilities, dementia and Alzheimer's) but also on medical conditions that are related to society and the social environment (e.g., depression and traumatising).

Notably, the excessive economic demands on the care institutions and the associated overburdening of support and care staff call for new models of action. Garden therapy as a holistic, low-cost measure that addresses the individual with all his or her senses offers a solution with a high success rate accompanied by relatively high job satisfaction on the part of staff.

MEMORY TRAINING

Regular memory training can help to maintain the mental abilities of people suffering from dementia for as long as possible.

In memory training, it is essential for the focus to be on the joy of life, self-esteem and recognition. It is important to promote those areas where those affected are still competent. Exercises that overburden them and consequently trigger stress and frustration are completely unsuitable. It is not about “performance” but playful training of brain functions.

In the early stage of dementia, it is still possible to use many different training options. Some people prefer to do training in a group. Efforts can be made to encourage relatives and friends to join in. In the advanced stage, attempts can be made to maintain and stimulate mental activity with very simple training programmes. A consistent effort should be made to connect with memories and feelings.

Memory training for relatives

Relatives of people suffering from dementia are often interested in training programmes that can prevent the onset of dementia. Unfortunately there is still no way of avoiding dementia by means of training, diet, etc.

However, scientific studies show that regularly training mental abilities, such as speech, logical thinking, new and old memories, attentiveness and concentration, etc. makes it possible to maintain mental capacity for a longer period.

Furthermore, it is recommended that the training of mental abilities be supplemented with physical exercises (including walks in fresh air) and a balanced diet.

ART THERAPY

Drawing, painting and designing can enable people with dementia to express their feelings and find relaxation. The possibility of expressing oneself artistically has a positive impact on the quality of life and can promote self-esteem. Moods and feelings can be expressed.

Consulting art therapists

This type of therapy should be performed under the guidance of art therapists. Relatives can also obtain advice for care in their own four walls. It is essential that those suffering from dementia enjoy the activity.

In the early phase of the disease, drawing and painting are possible, either freely or on the basis of motifs and patterns. Art therapists have seen positive experiences with watercolour painting. In a creative activity, it is useful to try out many different options. The artists should be able to determine motifs and painting techniques themselves.

Art therapists observe the positive or negative responses and feelings arise, and they address them. It is not about perfect works of art but about stimulating people with dementia and creating happy moments.

PHYSIOTHERAPY

Through different exercises, attempts are made to maintain and boost mobility, strength, balance and much more.

Physiotherapy is useful if the mobility and functional capacity of the person is at risk as a result of a disease. It uses not only the person’s own body movements but also the exercises guided by the therapist in order to cure, alleviate and prevent diseases.

Physiotherapy comprises therapeutic procedures that use exercise, warmth and light.

It can also be conducted in the form of group therapy, e.g., as exercise therapy with the aim of maintaining and reinforcing mobility, strength, balance, etc. It is important that the participants have fun doing the exercises and that they promote the enjoyment of physical mobility. Generally speaking, whether it takes the form of gymnastics, a walk or sports, physical exercise has a positive impact on the body and mind.

MUSIC THERAPY

Listening to music or making music gives pleasure, brings back memories and is a way of expressing oneself.

Music is a particularly good way to reach people with dementia. The person is pulled out of the state of apathy, and memories return. Patients can still recall the lyrics of songs learned at school, even though they no longer know what they did an hour ago. Music enables communication with people who can now only express themselves in an inadequate verbal manner. Music addresses feelings, and it can stimulate or calm and express joyful or sad moods.

This is the basis upon which specially trained music therapists work. However, caring relatives or volunteers in support groups can also implement many music therapy ideas in everyday care situations.

Some ways of using music therapy in everyday routine are

- singing together;
- playing instruments;
- listening to music together.

And music can also be helpful for relatives.

Singing together

Singing together connects people. Singing is fun, brings back memories and improves mood. If people with dementia can still remember song lyrics from their childhood and youth, they discover that they still have abilities. This certainty strengthens their self-confidence.

Playing instruments

Persons with dementia who used to play a musical instrument can be encouraged to try it again. However, in doing so, it is important to avoid exerting pressure to perform. Perhaps someone is “just strumming” on an instrument but finds a way of expressing their own feelings. Music therapists also use simple instruments, such as drums and sound bowls with which sounds can be produced even without prior knowledge.

Listening to music together

Be it in front of a radio, on a mobile phone or in a concert hall, there are many ways of listening to music with others. In doing so, it is important to tie in the habits and preferences of those affected. Certain pieces of music can remain emotionally powerful for one's entire life because they are associated with key memories, e.g., church services, dancing fun or the purchase of a first record.

For this reason, therapists and relatives should endeavour to find out something about the musical biography of those affected. Does the person suffering from dementia prefer jazz, classical music or pop songs? Was someone an active member of a music society, choral society or dancing club? Or was music relatively unimportant to them?

Music can also be helpful for members of the family

Caring relatives of people suffering from dementia are often physically and emotionally very stressed and exhausted. This is where music can help them to relax and create distance from everyday life. For this purpose, there are many options available: listening to music at home, attending concerts, making music, singing in a choir, etc. Many organisations, societies and self-help groups for people with dementia offer so-called dance cafés where those affected and their relatives have fun together.

Music therapy in practice

Pieces of music that are significant for those affected tend to activate memories and feelings. The aim is to activate emotional and communicative processes and thereby expand the capacity for experience.

ANIMAL-ASSISTED THERAPY

Addressing all the human senses with animals triggers a contact process that has a positive impact on the cognitive, social and emotional condition of people suffering from dementia. Animal-assisted therapy (also referred to as pet therapy) is recommended for people suffering from dementia because animals address abilities that are scarcely affected by the disease or not at all. Via the senses—sight, smell, hearing and especially touch—effects are triggered that have an excellent impact on the emotional perception of people suffering from dementia.

Interacting with animals

Stroking, touching and observing an animal gives the person a feeling of security, companionship, intimacy and reliability. That improves well-being.

Especially when it becomes more and more difficult for people suffering from dementia to communicate, animals still let them communicate and share feelings. By looking after animals, people with dementia can experience themselves as being capable, in line with their existing abilities. Brushing the animal's fur or feeding the animal are meaningful tasks. By assuming these responsibilities, the day takes on meaning. In addition, these tasks provide structure and also lead to cognitive stimulation on account of the daily routine. Depressive tendencies and aggression can thus be reduced.

It is important to acknowledge that the animal is a living creature with needs. For this reason, acquiring a pet should be well considered, and the person with dementia should never be solely responsible for the animal. Anyone who would prefer contact with animals on a casual basis can make enquiries with the local animal shelter as to whether voluntary dog walkers or cat petters are needed. A visit to a cat café also provides low-threshold, short-term interaction with four-legged friends.

HOW CAN MEDICINES HELP?

Medicines cannot stop the course of the disease, but they might delay it. In case of medicinal treatments, those affected, relatives and medical specialists must communicate well with one another.

For all stages of the disease, there are medically prescribed medicines whose effects have been confirmed by studies. The accompanying symptoms of the disease can also be treated. In the course of a dementia disease many patients have symptoms — to a varying degree — that can be treated with suitable medicines.

TREATMENT OF THE UNDERLYING DISEASE DEMENTIA

So-called anti-dementia drugs are medicines that can stabilise the course of the disease and delay its progression. Consequently, the independence of persons affected can be maintained for a longer period. The need for support and care and the burden on caring relatives can thus be reduced.

Medicinal treatment is not successful in all people suffering from dementia. However, it can be referred to as successful if the mental capacity does not deteriorate for some time.

In any event, it is advisable to consult with the doctor on all issues regarding medicines, dosage, side effects and a possible change of product and to monitor the effect of the medicine closely.

TREATMENT OF ACCOMPANYING SYMPTOMS

Accompanying symptoms of dementia diseases are symptoms that do not involve mental capacity but have a considerable influence on mood and behaviour. They can be very stressful both for those affected and for caregivers. They include depression, fear, unrest, aggressiveness, insomnia, delusions or sensory illusions.

Treatment with appropriate medicines can reduce or eliminate these symptoms. In addition, it is advisable to discuss with the doctor whether non-medicinal treatments would be suitable, and if so, which ones.

For example, one should consider whether sleeping pills are really necessary or whether walks and activities in the home would be sufficient to ensure that in the evening the patient feels tired and can fall asleep. In the case of depressive mood, are medicines necessary or what activities would help make the person suffering feel happy?

Relatives play an important role in treatment. They should monitor carefully what effects or adverse side effects occur and notify the doctor. If necessary, the dose must be altered or the medicine must be discontinued.

RELIEF FOR RELATIVES



Eighty percent of all persons requiring care in Austria are cared for by their relatives. Providing care to a relative can be very fulfilling. However, it can also involve major challenges because it calls for extensive knowledge and tremendous resilience. Unlike professional care there is no emotional distance here, and this makes the care more intimate, more personal and closer but that is precisely why it can also be more stressful and more frustrating.

Pay attention to your energy level; only then can you share some with others

Caring relatives often feel that they have to be available to the person being cared for 24 hours a day. The inherent risk is that the caregiver's own needs will increasingly be pushed aside. That can be dangerous because nobody is helped if the caregiver repeatedly reaches or goes beyond their limit. Only someone who has enough energy and strength can share some of it with others. For this reason, it is not selfish to look after one's own well-being, to meet friends, to interact with others — it is tremendously important self-care that makes caring for others possible in the first place.

Don't expect yourself to be perfect and don't expect yourself to always function well

Take advantage of discussions with a doctor or therapist, cooperate with professional organisations and allow yourself to relax and recharge your battery. Your body and well-being, but also the person you are looking after, will be grateful to you.

Discussion groups for caring relatives make it possible to reflect on one's own situation and get ideas about how to organise everyday care.

Holiday from care

From time to time, everyone needs a holiday, relaxation and change from everyday routines. A holiday offers an opportunity to recover physically and mentally and to recharge batteries. If time off becomes necessary, the family members should arrange a temporary replacement. Other relatives or friends may be considered, but also an outpatient care service or a care facility nearby, where family members in need of care can be properly looked after during a holiday.

Even if caring relatives find it difficult to take time off, it is important to remember how important recovery phases are for your well-being and your health. After all, only healthy and balanced individuals can provide attentive and loving care.

Have the courage to review the situation

However, if you notice that you are regularly at your wit's end, don't hesitate to look for new solutions together with your relatives. Perhaps it would be helpful if you were to be assisted by in-home help or a mobile care service at regular intervals. Perhaps other members of the family, friends or neighbours of the patient could help to provide the care. Or perhaps it would be the right decision to apply for a place in a care home. A decision regarding who will provide the care at home and for how long is always specific to the individual case and can only be made within the family; in doing so, don't let yourself be influenced or even pressured.

PROFESSIONAL ASSISTANCE

Many people have the desire to lead a largely self-determined life for as long as possible if support and care should become necessary. At the same time, we live in an ageing society: The number of people requiring care and aid will double over the next 20 years. What is more, family structures are changing. More and more caring relatives are faced with a double burden because they work. Women in particular, who provide two thirds of all the care to relatives, are exposed to considerable pressure.

People with dementia and their relatives have access to mobile, partially inpatient and fully inpatient support options from various providers. Volkshilfe provides many different services all over Austria so that elderly people can retain their independence up to a very old age and so that caring relatives are relieved of the burden.

VOLKSHILFE OFFERS:

- Mobile services for care and support at home: Home nursing, home help;
- arrangement of emergency telephones;
- meals at home;
- long-term and short-term care in care homes and senior citizen centres;
- 24-hour personal support (www.pflegen.at);
- day centres, also specifically for dementia patients;
- assisted / supervised living arrangements;
- support, relief and accompaniment of caring relatives;
- visiting services;
- free consultations for persons with dementia and their relatives.

FINANCIAL AID

AUSTRIA'S DEMENTIA AID FUND

The need for aid to assist persons suffering from dementia can be substantial. However, financially disadvantaged people are often unable to afford the necessary support or advisory services. That is why, together with a Swiss foundation, Volkshilfe has launched the Dementia Aid Fund Austria. Supervision hours or care resources, for example, can be financed with this unbureaucratic aid.

WHO CAN APPLY FOR FINANCIAL AID?

People who are suffering from dementia are entitled to financial aid. The application can be filed by the persons affected, by caring relatives, by family members or by other supporters. You will find all the information concerning the application form and the necessary documents at www.demenz-hilfe.at

HOW OFTEN IS AID PAID OUT?

Support can be paid out once a year. You can file an application for aid from the Dementia Aid Fund once every year.

HOW MUCH IS THE AID?

The amount depends on various criteria, such as medical condition and the income and expenditure ratio.

WHERE CAN I APPLY?

The best thing to do is contact a Volkshilfe advisory centre near you. Please take all the necessary documents with you. For this purpose, it is necessary to produce a doctor's letter (confirmation of the dementia disease), income statements from everyone living in the house and expenditure statements concerning dementia-specific expenses (bank account statements, invoices). It is also possible to download the application form from the website www.demenz-hilfe.at and send all documents by email to Volkshilfe in your state.

YOU'RE NOT ALONE

Coping strategies for relatives of people suffering from dementia



Why am I so exhausted?



Health causes

How do I handle my **health issues** that arise as a result of the care?

What can I do **for myself**?

What can help me?



I receive psychological support in the **self-help group**.

I receive **professional support** during the care to give me relief .

If I have medical symptoms, I go to the **doctor**.

Material causes

How do I handle **financial burdens** that arise as a result of the care?

How do I furnish the **flat** to make it dementia-friendly?

What does **meals on wheels** cost?

What does **mobile care** cost?

Where is the nearest **day centre** and what does it cost?

I ask my doctor for drop-in centres.

I learn about support and listen to the experiences from other participants in the **self-help group**.

I receive information from public offices and the Ministry of Social Affairs regarding **financial aid and fee exemptions**.

I receive information about **care leave / part-time care** from the Austrian Health Insurance Fund, the Ministry of Social Affairs or the Chamber of Labour.

A **social worker** helps me to file applications.

I receive **financial aid** from the Dementia Aid Fund.

Social causes

How do I use my **networks**, family and friends in order to give me relief?

Whom can I ask for **help**?

How can I still participate in **social life**?

How can I still go on **holiday** with my **partner**?

I find **new acquaintances** in the self-help group, which do me good.

I use **Leisure Buddies or Everyday Companions** to give me relief on an hourly basis.

I have a **WhatsApp group** that supports me.

I use visiting services and care during the day to recover at certain times.

I take advantage of **dementia holidays** being offered in order to get away and relax together.

Interpersonal causes

How do I handle the **changes in behaviour of my family member suffering from dementia**?

I give my everyday routine plenty of **structure**, with reminders and orientation aids.

I attend **information events** that explain how to communicate properly.

I receive **psychological support** to handle aggression differently.

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und Konsumentenschutz

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