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1. What is dementia? What forms can it have?

In the Federal Republic of Germany, there are currently over 1.5 million people suffering from dementia, with up to 25,000 cases in the Saarland. According to the recent estimates, the number of sufferers will double by 2040 if no therapy breakthrough can be achieved.

The term “dementia” comes from the Latin expression “de mens”, meaning “without spirit”. Dementia is one of the most common age-related mental illnesses. Dementia is a progressive disease and one of the most frequent reasons for people being in need of care. As a rule, there is no cure.

When a person suffers from dementia, their mental capabilities start disappearing. As a consequence, they experience problems with their daily routines. A person has dementia if they have been having thinking-, memory- and orientation-related problems for at least six months.

Apart from the continuous distinct impairment of the short- and long-term memory, at least one further disorder can be identified in most cases of dementia:

- Decrease in the judgement and thinking capacity
- Speech disorders/speech comprehension disorder (aphasia)
- Recognition disorders (agnosia)
- The sufferer experiences trouble performing daily routines/handling objects (apraxia)

If a person experiences short-term states of confusion (e.g. due to lack of fluids, high or low blood sugar, fever, side effects or medication interaction, alcohol or sleeping pills withdrawal or severe traumas), this is called delirium (state of strong confusion) rather than dementia.

When somebody is suffering from dementia, it often results in severe stress for the person’s relatives who will have to care for them, as well as for the persons effected.

With regard to dementia that leads to a reduction of nerve cells in the brain, the most frequent form of it is **Alzheimer’s disease** (60%). There is also **vascular dementia** (20%), mixed forms (10%) and many other, rather rare forms. There are also secondary dementia forms – this means that the person’s state is caused by other diseases or factors some of which may be curable.

2. Diagnosis and Treatment of Dementia

Detecting Dementia at an early stage is important in order to

- detect curable diseases in due course and to treat them.
- to slow down the progression of incurable diseases and to be able to use the existing resources for a longer period of time.
- to allow the person to adapt their life to the new situation and to initiate preventive measures.

In most cases, the path to the diagnosis leads via your GP (general practitioner) to a specialist in

a certain area of medicine (neurologist, psychiatrist or a specialist clinic).

In order to perform a diagnosis, the doctor must first rule out other diseases or causes for the loss of mental capacities. They will have a discussion with the sufferer and their relatives, carry out all the necessary tests (e.g. mini-mental state examination, drawing clocks) and propose further examinations.

If dementia should be confirmed, the treatment will be based on life quality improvement measures and support for the relatives. Medication such as anti-dementia drugs aim at slowing down the disease's progression. For related symptoms (depression, anxiety, lack of energy, aggression, sleep disorders), the doctor can also propose certain psychotropic drugs. If the sufferer is already taking other medication, it should be checked whether it is still suitable for dementia patients, and a new prescription will be issued. An important criterion is the relief of the psychological strain.

3. Dealing with People Suffering from Dementia

Dealing with people suffering from dementia is problematic for many, because their loved one starts changing. If dementia increasingly causes the sufferer to lose their mental capacity, the illness often starts by affecting the person's short-term memory. They forget something that only happened recently, and the periods of time that it takes them to forget become shorter as dementia progresses. In case of Alzheimer's disease, it is the long-term memory that becomes increasingly emphasised, and the sufferers often talk about what happened in the past.

As the disease progresses, the sufferers spend more and more time in their own world, frequently in their own past. Therefore, their relatives should learn to accept people with dementia the way they are. It is helpful to be familiar with the major events in their life in order to establish better rapport with the sufferers.

In order to improve their interaction with people with dementia and to help them, their relatives should adhere to the following basic tips:

- People suffering from dementia need social interaction and company
- Relatives should recognise the sufferer's right to believe what they think is true
- No confrontation with reality
- People suffering from dementia react to how something is said rather than to the actual content of the statement
- Try to refrain from discussions (it is not about who is right)
- Often, accusations are not meant personally and should be ignored whenever possible
- Days should be structured (structures make the sufferers feel certainty again, e.g. having meals at the same time, going to the toilet before or after the meal)
- Encourage the sufferers to engage in activities they are still capable of performing
- Praise people with dementia for what they do (the result is not important)
- Ensure the sufferers drink enough fluids and receive suitable meals

Many relatives say that they no longer have freedom to do anything else and must be available 24/7. This is often a serious burden for the nursing relatives. Therefore, it is very important that they request help to get some rest and stay healthy.

Nursing relatives should seek advice regarding aid and relief from their burden, as well as available funding options. To receive further information about dementia and about how to deal with people suffering from it, relatives should attend special training courses (those nursing courses are free of charge).

Communicating with people suffering from dementia can often be a complicated matter, but you can make it simpler by adhering to the following rules:

- Approach people suffering from dementia slowly and in a friendly manner
- Try to create an atmosphere of tranquillity
- Communicate and explain what you are doing at any given moment
- Gestures, mimic and body language are often more important than speech
- Use physical contact cautiously and respectfully
- Always maintain eye contact when you speak, if possible on the same eye level
- Speak slowly and clearly
- Use simple, short sentences, avoid “either/or” constructions
- Use and repeat the words used by the sufferer
- Try to refrain from disagreeing with the sufferer and correcting what they are saying
- Avoid loud noises and sensory overload
- Use affirmative statements and positions

You will receive further, more detailed information by participating in trainings offered in the Saarland in a location near you. The employees of **nursing stations and advisory offices** will be happy to help you find a training point.

4. Relief and Support for Nursing Relatives

Why is relief so important?

Nursing relatives who have to support people suffering from dementia and experiencing mental changes face an especially difficult task. The burden that relatives of people with dementia carry is a different one from those caring for patients with severe chronic physical diseases. The special problems they are confronted with include challenging behaviour such as orientation disorders, reversal of the day-night rhythm, forgetfulness, anxiety, aggressiveness and change of the sufferer’s character. All this can be an additional burden when you nurse your relative at home.

For many people, nursing and supporting their dementia-stricken relatives means a great deal of strain – having to be available the entire time can lead to physical and mental problems.

Nursing and supporting people suffering from dementia at their home can only be successful if done by relatives who can also take care of themselves and stay healthy. Therefore, apart from providing the sufferers with suitable care, the nursing relatives should be ready to make use of relief offers.

Good relief offers for relatives include e.g. competent nursing advice, trainings, experience-exchange groups, home nursing offers, daily and short-term care. In the Saarland, a great deal of relief offers are available.

Advice for nursing relatives

Since January 2009, people have a legal right to receive free and independent nursing advice through the state-run nursing care insurance. In the Saarlouis District, it is especially the nursing station, as well as the advising dementia specialists of Saarlouis' Dementia Association (Demenz-Verein Saarlouis e.V.) that ensure that such help is available.

Specialised dementia advice services offer the following help for relatives and sufferers:

- Advice regarding any aspect of nursing and supporting people with dementia
- Providing information about the symptoms and available treatment of dementia-type diseases
- Information about dealing with people suffering from dementia
- Advice and support with submitting an application
- Advice and support with searching, selecting and getting access to the right services that provide nursing and support for the sufferers
- Planning and organising individual care
- Support of individual nursing arrangements
- Advice for adapting your home

You can receive advice in person, by telephone or through a house call.

The contact data of each district's nursing stations can be found in the address section.

Apart from that, further organisations can offer you **specialised dementia-related advice near you**, e.g. welfare organisations, your nursing care fund and nursing services.

Nursing courses for relatives

Nursing relatives or voluntary care workers can attend free courses offering information, advice, practical guidance, as well as a chance to exchange experiences. Also, a special training tailored to your individual case can be carried out at your home. Relatives of people suffering from dementia can find training offers near them in the Saarlouis district.

Groups of relatives for experience exchange

Groups for people nursing relatives with dementia offer you:

- A confidential platform for experience exchange with other relatives
- Information about dementia symptoms
- Tips for dealing with the sufferers in order to facilitate the nursing process
- Professional support and guidance, from one-off visits up to regular assistance
- Information about advice, support and relief options

The groups in the Saarlouis district meet up in various locations in regular intervals. Participation is free. Some groups offer their members the opportunity to bring people with dementia with them, and the sufferers receive support right there.

Home support and support groups (Low-threshold support offers)

These are support offers which involve specially trained workers supporting people with dementia on an hourly basis, either in groups (e.g. Dementia Café) or at home. They provide relief for the nursing relatives and support them by offering them advice. Low-threshold offers are offers e.g. by welfare organisations, care services as well as authorised private individuals.

Care services

Thanks to home care, people requiring care can receive it in their family environment. In Germany, it is always prioritised over inpatient care. People from the sufferer's social circle who provide care for them can be supported by or receive relief from professional care services or social stations against remuneration. Home care is provided by authorised care services.

Day care

Day care is intended primarily for people who have an especially strong demand for care and supervision. Visits from day care specialists in combination with home care can delay an impending stay at a care home or even help to prevent it altogether.

Day care specialists give patients the opportunity to engage in various collective activities under professional supervision (e.g. cooking, small DIY activities, singing, painting, physical activities).

Many people with dementia benefit substantially from being able to engage in activities in a group.

The sufferers feel more confident and their mood improves if they can satisfy their basic needs, such as being useful and feeling needed. Also, such non-drug-related offers help to fight symptoms such as anxiety, aggressiveness and depressive moods and influence the disease's progression in a positive way.

Often, relatives cannot imagine how people with dementia manage to stay in an institution, even if they get back home when the day is over. Often, sufferers say that they fear they might get "taken away" or they say they want to "go home". Nevertheless, it is important that nursing relatives make sure they always get sufficient relief. This will help them stay healthy for a longer period of time and consequently to provide care for their dementia-stricken relatives.

Patients should also feel at home at their daily care facilities to make sure that the change of environment causes as few problems as possible. If the facilities do not feel like care facilities, but rather like a place the sufferer would normally spend their days at, it will make people with dementia feel comfortable. It can be helpful to arrange a trial day or a few hours, just to "get a feel".

As a rule, daily care facilities are open from Monday to Friday from 8 am to 4:30 pm, with some facilities offering extended opening times and also care during the weekend.

Day care services for people with dementia should include:

- Transportation to the facilities and back home
- Meals
- Basic and treatment care
- Therapy and rehabilitation offers
- Daily routine and various day time activities in the course of company therapy
- High patient-staff ratio
- Nursing in small groups
- Sufficient number of employees who are specially qualified to deal with people suffering from dementia
- Specifically prepared care based on the patient's biography
- Collaboration with relatives
- Advice for nursing relatives, including house calls if required

Short-term care

A patient may require a short-term care stay if the care they usually get at home is temporarily unavailable in the amount they need and if part-time inpatient care is not sufficient, e.g. following an inpatient hospital treatment or in certain emergencies.

Short-term care is offered by care facilities which have concluded an agreement with nursing care funds. They should also be suitable for people with dementia. Relatives should arrange a visit in due course and enquire about the care concept and the occupational activities offered. They should

also ask whether the staff has been trained to work with people suffering with dementia and whether the sufferer's special needs will be taken into account.

5. Inpatient Care

Care home

If the sufferer cannot be cared for at home due to the state of their health or due to their relatives being ill, they should be moved to a care home.

In such situations, relatives often feel guilty for letting the sufferer go. However, those feelings are mostly unjustified, as they had done a lot to make the person feel at home.

In order to gain an impression about whether a care home is suitable for the dementia-stricken person, the relatives should in due course arrange a visit and enquire whether the nursing concept, the activities offered, the premises and staff's training are suitable for patients suffering from dementia.

Dementia in hospital

People are usually admitted to a hospital if they have acute, mostly physical symptoms or diseases that necessitate hospital treatment.

Often, however, no information regarding dementia-related restrictions or the situation in the patient's family is available for people with dementia admitted to a hospital due to a physical illness or an injury. Therefore, for patients with dementia and their relatives, a hospital stay frequently leads to a crisis. A delirium is also a distinct possibility (= state of strong confusion). Therefore, the hospital stay should be as brief as possible.

Dementia-related restrictions and behaviours can make the nursing care and the medical and therapeutic treatment provided at the hospital more difficult. For this reason, the relatives should draw the staff's attention to the sufferer's special habits (e.g. food preferences, medication, sleeping habits). Many hospitals also offer the "Rooming In" option, i.e. a contact person can stay with the patient.

In the past few years, there has been an increasing number of projects (some of them in the Saarlouis district) aimed at improving the situation of people with dementia staying at hospitals.

Geriatric/psychiatric clinic

Specialised geriatric clinics can also admit people with dementia for short periods of time for diagnosis purposes or if, apart from dementia, patients have other symptoms that require intensive medical treatment. Specialised psychiatric clinics, some of which have gerontological psychiatric departments, accept people with dementia and, among other things, can offer them treatment of behavioural disorders (e.g. aggressiveness). A further reason for being admitted or for an emergency hospitalisation is dementia sufferers being a hazard to themselves or to others and their GP or office-based neurologists not being able to treat them.

6. Nursing Care Insurance – Financial Benefits

According to Volume 11 of the German Social Code (SGB XI), those people will receive payments from their nursing care insurance who have been classified as belonging to one of the care levels and require assistance with their basic needs (personal hygiene, diet and mobility), as well as in their household. Benefits must be requested from the nursing care fund in charge. Thereupon, an examination will be carried out on behalf of the fund, in the course of which the entitlement to receive benefits will be verified.

The classification into one of the three care levels is based on the amount of time spent on the required care measures:

- Care level I: At least 90 minutes, from which at least 45 minutes are spent on tending to the sufferer's basic needs
- Care level II: At least 3 hours, from which at least 2 hours are spent on tending to the sufferer's basic needs
- Care level III: At least 5 hours, from which at least 4 hours are spent on tending to the sufferer's basic needs

If, following an examination, the nursing care fund should not recognise the patient's belonging to any of the care levels, but decide that they do have "significant general need for care" pursuant to Paragraph 45a SGB XI (e.g. due to dementia), the patients may still be entitled to benefits of the so-called "Care Level 0". Apart from that, people with this level of requirements receive higher benefits for care at home on Care Levels I and II.

Care at home – Benefits

The recognition of "**significant general need for care**" according to Paragraph 45a SGB XI by the nursing care fund is required for receiving the following benefits (as of 01/01/2015).

Care allowance

Care at home by relatives or other people:

Care Level 0	123 €
Care Level I	316 €
Care Level II	545 €
Care Level III	728 €

Benefits in kind

Care at home by a recognised care service (costs are covered directly by the nursing care fund):

Care Level 0	231 €
Care Level I	689 €
Care Level II	1298 €
Care Level III	1612 € (in cases of hardship up to 1995 €)

Combined benefits

If the sufferer does not use up the benefits in kind, they can also receive a percentage of the care allowance. This amount will be calculated as a percentage of the provided benefits in kind.

Care aids

People requiring care are entitled to receive care that involves the use of care aids for facilitating the care process or for alleviating the symptoms suffered by the patients or care aids which enable the patients to lead more independent lives (e.g. bath lifts, commodes). For consumable aids (e.g. incontinence pads), the nursing care fund can pay a monthly contribution of up to 40 €.

Measures for improving the living environment

Nursing care funds can make a financial contribution for measures that improve the patient's individual living environment to facilitate the nursing or to enable them to lead independent lives (e.g. installation of a walk-in shower). This contribution can be up to 4000€ depending on the costs of the respective measure. The contribution can be requested again if the nursing situation changes, the nursing care fund must approve the measure prior to submission of the request.

Substitution care

If a caregiver is not available to provide care due to holiday or illness, the nursing care fund will pay the costs of the required substitution carer for a maximum of 6 weeks per year. A half of the (percental) care allowance will be paid for up to 4 more weeks.

Requirement: Before the caregiver can profit from substitution care for the first time, they must have cared for the patient at the patient's home for at least 6 month.

Substitution care can be provided by relatives, neighbours or other people or by professional services. If substitution is provided by distant relatives, neighbours or a care service, the nursing care fund will pay for a maximum of 6 weeks, up to 1612€ per calendar year. If substitution care is provided by close relatives, the nursing care fund can only pay expenses in the amount of 1.5x

care allowance. If, when providing care, the relatives really incur expenses such as travel costs or loss of earnings, the nursing care fund can cover those costs up to the above-stated amount. Substitution care can also be used on an hourly basis. Apart from that, up to 50% of the yet unused amount for short-term care can be used.

Day and night care

Semi-inpatient day and night care for ensuring or supporting care received at home:

Care Level 0	231 €
Care Level I	689 €
Care Level II	1298 €
Care Level III	1612 €

Semi-inpatient care also comprises the necessary transportation of the patient from their flat to the day and night care facilities and back. The nursing care fund compensates the care-related expenses and pays for the social care and the medical treatment. Costs for food and accommodation for people with dementia can be refunded via the so-called “additional care benefits” (cf. Paragraph 6).

The day and night care benefits can be combined with the care allowance or benefits in kind. The amount of the care allowance or benefits in kind remains the same as long as the day/night care amount does not exceed the maximum amount. Thus, the combined benefits can be up to 200%.

Short-term care

If care at home is temporarily impossible, short-term care can be provided in full-time inpatient facilities for 4 weeks per calendar year (e.g. following hospital treatment or in cases of emergency). Apart from that, this time can be extended to eight weeks as part of substitution care benefits that have not been used yet.

The nursing care fund pays up to 1612€ for care-related expenses, social care and medical treatment. Food and accommodation costs cannot be paid, but they can be funded with the help of the additional care benefits. As part of short-term care, 50% of the care allowance will be paid for up to four weeks.

About the Care Reform

The German **Care Boost Act I**, which came into effect at the beginning of 2015, has already brought about some significant improvements in the field of care – especially the extension of the benefits for people requiring care and their relatives.

It is expected that the planned **Care Boost Act II** (2017) will introduce a new definition of the need for care (replacement of the previous three care levels by five needs-oriented care degrees) and a new examination procedure.

Instead of three care levels, it is planned to introduce five, which will be more suitable for individual care requirements. No division into physical, mental and psychological impairments shall then be made when establishing the care requirements. The decision whether a person requires care shall be based on the level of their independence.

Care requirement based on the care levels after the introduction of Care Boost Act II in 2017

Care degree	Basic care (SGB XI)	Psychosocial support	Help during the night	Pre-sence throughout the day
Care degree 1	27–60 minutes	up to 1 x daily	no	no
Care degree 2	30–127 minutes	up to 1 x daily	0–1x	no
Care degree 2 with limited ability to perform daily routines	8–58 minutes	2–12x daily	no	under 6 hours
Care degree 3	131–278 minutes	2–6x daily	0–2x	under 6 hours
Care degree 3 with limited ability to perform daily routines	8–74 minutes	6x daily up to permanently	0–2x	6–12 hours
Care degree 4	184–300 minutes	2–6x daily	2–3x	6–12 hours
Care degree 4 with limited ability to perform daily routines	128–250 minutes	7 up to more than 12 x daily	1–6x	around the clock
Care degree 5 with limited ability to perform daily routines	245–279 minutes	More than 12x daily	min. 3x	around the clock

Additional care benefits

People requiring care who are being nursed at home and who demonstrate a “significant demand for general supervision and care” (e.g. due to dementia-related limitations of their abilities) receive additional care benefits in the amount of **104 €** or **208 €** per month according to Paragraph 45b of

SGB XI. The degree of their care requirement is determined individually by recommendation of the Medical Review Board of the Statutory Health Insurance Fund.

Care benefits are benefits in kind allocated by bodies or persons authorised in accordance to the federal state laws as part of so-called “low-threshold care offers”. Those are e.g. offers for provision of care at home on an hourly basis or in a group outside the patient’s home. Apart from that, food and accommodation expenses (e.g. in case of day or short-term care) can be compensated with the help of care allowance. Amounts not spent within a calendar year can be transferred, but must be spent by 30 June of the following year.

Since 2015, there have been further, additional relief benefits to facilitate the patients’ everyday life and to support the caregivers, e.g. by means of household services or everyday companionship (relevant offers are regulated in accordance with the federal state laws). If the above-stated amounts have been used up, up to 40% of the benefits-in-kind amount can also be spent on additional care and relief services.

Caregivers’ social security benefits

Under certain conditions, caregivers nursing one or more persons at their home can receive statutory payments from their pension insurance. Apart from that, nursing relatives are entitled to receive the statutory accident insurance for any activities and transportation performed as part of nursing.

Care period and family care period

By virtue of the changes made to the German **Care Period Act** (PflegeZG) on 1 January 2015, nursing relatives are entitled to receive leave of absence for up to 10 working days from their employer in situations where an urgent care requirement arises (“short-term work incapacity”). They can also receive benefits to cover their loss of earnings, the so-called “Care support allowance”. Apart from that, they can receive a partial or full leave of absence for a period of up to 6 months to perform their nursing duties. Thanks to the changes made to the **Family Care Period Act** (FPfzG), they can also receive a partial leave of absence for up to 24 months to care for a close relative, provided they work at least 15 hours weekly. In both cases, they can receive an interest-free loan as a partial compensation for their loss of earnings.

Apart from the above-stated benefits received in connection with the nursing care insurance and the Care Period Act/Family Care Period Act, people with dementia are also entitled to receive benefits from other providers of social benefits/services (health insurance, rehabilitation, social welfare) under certain circumstances. Please seek advice to find out more.

7. Legal Precaution/Care

It is especially in cases of dementia with the patient losing their mental capacity that a time comes when the sufferer loses their grip on reality and their relatives must be able to act in their capacity from the legal point of view.

Various legal options are available in this case, e.g.:

Precautionary power of attorney/General power of attorney
Health care proxy
Living will
Legal support

The guardianship authorities of your federal state, guardianship courts and guardianship associations in individual districts can offer you free advice and help in this regard.

8. Contacts

State-wide operating centres

Landesfachstelle Demenz Saarland
(The Saarland Dementia Consulting Centre)
Ludwigstr. 5
66740 Saarlouis
Phone: 06831 – 48818-14

Saarländischer Integrationsrat – SIR
(The Saarland Board of Integration)
Altenkesseler Str. 17/C1
66115 Saarbrücken
info@integrationsrat-saarland.de

Saarlouis District

Spezialisierte Demenz-Fachberatung im Landkreis Saarlouis
(Specialised Dementia Consulting for the Saarlouis District)
(on behalf of the Nursing Station of the Saarlouis District)
Demenz-Verein Saarlouis e.V.
(Saarlouis Dementia Association)
Ludwigstr. 5
66740 Saarlouis
Phone: 06831 – 488180

**Pflegestützpunkt im Landkreis Saarlouis
(Nursing Station of the Saarlouis District)**

Choisyring 9
66740 Saarlouis
Phone: 06831 – 120630

Saar-Palatinate District

**Pflegestützpunkt im Saarpfalz-Kreis
(Nursing Station of the Saar-Palatinate District)**

Am Forum 1
66424 Homburg
Phone: 06841 / 104 - 80 76

Merzig Wadern District

**Pflegestützpunkt im Landkreis Merzig-Wadern
(Nursing Station of the Merzig-Wadern District)**

Bahnhofstr. 27
66663 Merzig
Phone: 06861 / 80 477

Saarbrücken District

**Pflegestützpunkt im Regionalverband Saarbrücken-Mitte
(Nursing Station of the Saarbrücken-Mitte District)**

Stengelstr. 12
66117 Saarbrücken
Phone: 0681 / 506 - 53 22

**Pflegestützpunkt im Regionalverband Saarbrücken-West
(Nursing Station of the Saarbrücken-West District)**

Rathausstraße 4-6
66333 Völklingen
Phone: 06898 / 13 55 55

**Pflegestützpunkt im Regionalverband Saarbrücken-Ost
(Nursing Station of the Saarbrücken-Ost District)**

Sulzbachtalstr. 81
66280 Sulzbach
Phone: 06897 / 9 24 67 - 98

St Wendel District

Pflegestützpunkt im Landkreis St. Wendel (Nursing Station of the St Wendel District)

Mommstr. 27

66606 St. Wendel

Phone: 06851 / 801 - 5251

Neunkirchen District

Pflegestützpunkt im Landkreis Neunkirchen (Nursing Station of the Neunkirchen District)

Knappschaftsstr. 1

66538 Neunkirchen

Phone: 06821 / 10 26 74

Specialised dementia-related advice near you is also offered by social welfare associations, nursing care funds and nursing services.