



**Englisch**



## **Demenz – In der Weite des Vergessens**

Hilfen für pflegende Angehörige







Prävention in NRW | 61

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## Preface

Caring for a family member suffering from dementia is a particular challenge. Besides providing physical care, it is important to understand the illness and slowly let go of how the family member used to be. A process of saying goodbye begins.

Our concern in this brochure is to provide family members caring for a dementia patient with a practical guide. The aim is to ensure that the patient experiences as much quality of life and dignity as possible, and that the family caregiver remains healthy, despite the difficult task.

We will try to accomplish this by imparting knowledge, offering practical assistance and with a little poetry. Mutual appreciation and a healthy portion of nonchalance should help to strengthen the position of family caregivers and restore a degree of welcome normality to life.

Yours,  
The Team from Unfallkasse NRW



# 1 The ten most frequent questions family members ask about dementia



## 1.1 What is dementia?

The term 'dementia' originates from the Latin and means 'being out of one's mind'. In the medical world, dementia is frequently used as a generic term for various symptoms and pathologies. They refer in particular to a deterioration of mental faculties in the following areas:

### Memory

Dementia patients are unable to create new memories and forget things they once knew.

### Orientation/judgement

The persons have difficulty with spatial (e.g. they are unable to find their way home or to the bathroom) and temporal orientation (they are unable to name the current date, day of the week, year or season and also mistake the times of the day). Their judgement may also be impaired, e.g. they are no longer able to appreciate dangers to themselves or others.

### Changes in behaviour/mood

From the perspective of neutral observers, dementia patients often behave inappropriately in a variety of situations. Sometimes they react angrily, stubbornly or irately, while on other occasions they withdraw and seem apathetic. One of the reasons may be that as the disease progresses, the persons gradually lose an appreciation for who they are, as well as their self-confidence. They notice an increasing inability to cope with



everyday life on their own and receive the same feedback from people around, especially at the start of the illness. Because the persons notice these things, it is natural that they respond irritably or angrily – without there being an obvious reason for family and friends.

#### Difficulties with routine tasks

Often the persons will have difficulty managing simple tasks like cleaning their teeth or getting dressed and undressed. Dementia patients lose the ability to contextualise individual actions (e.g. removing, cleaning and replacing a dental prosthesis), which makes them seem like impossibly complex tasks. As a result, they can only complete these actions with instruction from the family caregiver. Reasoning gradually deteriorates as well.

#### Difficulties with routine skills

The persons are no longer able to manage their everyday lives. Many things can be concealed or trivialised in the early phase of the illness. But it gradually becomes impossible as the disease takes hold (example: children learn at an early age to open the fridge – they know that the yoghurt is kept there. A dementia patient forgets the significance and purpose of a fridge and might use it to store his socks).

Actions that used to be taken for granted are no longer possible. Toothbrushes are not recognised correctly and are used instead as nailbrushes. Dementia patients might eat their food cold, having forgotten that it needs to be warmed up. They eat bread on its own, as they no longer know how to spread the topping or hold a knife.

#### Language

Dementia patients have trouble remembering the names of things and problems understanding spoken and/or written language. It is important to distinguish between difficulties with recognition or just finding the right word. For instance, a dementia patient who perceives a glass as nothing other than a hollow, transparent receptacle is experiencing a difficulty with recognition and will be unable to grasp its purpose. Hence, they will be equally unable to perform the appropriate action (drink from it). But if the person realises that the transparent receptacle is used for drinking, he will still use it for the right purpose, even if he is unable to remember its name. This is an example of difficulties finding the right word.

### 1.2 Which forms of dementia exist?

Broadly speaking, a distinction is made between two types:

#### Primary type (approximately 85 to 90 percent of cases)

This type directly affects the brain. There are two main groups within the primary form of dementia:



### Neurodegenerative dementia

The term 'neurodegenerative' is made up of the words neuron (nerve cell) and degeneration (deterioration). Nerve cells die in this type of dementia. The cell death is caused by protein deposits between the nerve cells. This causes disturbance and regression in the contact points between the cells, leading to atrophy of the nerve cells themselves. Initial symptoms of the disease will become evident when ten percent of the brain's contact points no longer work properly. Alzheimer's disease is the most common form of neurodegenerative dementia, which will be dealt with later on in this brochure.

### Vascular dementia

'Vascular' comes from the Latin word for 'vessel'. In this case it means the blood vessels that supply the brain with oxygen and nutrients. The brain will no longer receive what it needs if these supply lines are obstructed, for instance due to deposits in the blood vessels or vascular occlusion. When larger deposits form, the walls of the blood vessels become significantly thicker, making them brittle and more likely to burst. This causes a brain haemorrhage, which can also lead to dementia.

### Alzheimer's disease

Accounting for around 60 to 70 percent of all cases, Alzheimer's is the most common form of dementia. It was named after the neurologist (doctor specialising in the nervous system) Alois Alzheimer, who described the pathology for the first time in 1906. This type involves the formation of round protein deposits in certain regions of the brain. They are called amyloid plaques. Thread-like protein deposits also form between the cells of the brain, which are destroyed increasingly as these structures develop. The illness can emerge from middle age onwards. Orientation difficulties, speech disorders and forgetfulness may occur in very early stages, depending on which region of the brain is affected.

### Secondary type (approximately 10 to 15 percent of cases)

The brain itself is not affected directly in this type of dementia. It loses its function because another organ is diseased (a different underlying condition). The brain is therefore responding to a physical problem. It may be a metabolic disorder (e.g. hypothyroidism), organ failure (e.g. kidney failure) or deficiencies (dehydration). Consulting a neurologist to obtain a diagnosis is essential in all cases, as the secondary type is often curable!

### Mixed types

Dementia rarely occurs in a 'pure' form. For instance, patients suffering from Alzheimer's (neurodegenerative) may also have damage to the blood vessels in the brain (vascular). Other patients with a circulatory problem in the brain might show protein deposits between the nerve cells as well.

## 1.3 What are the first symptoms of dementia?

The first symptoms may be:

- Frequent repetition of the same question or story.
- Difficulties with routine tasks such as making telephone calls, cooking, setting the table or fitting a light bulb.
- Orientation problems, particularly in unfamiliar places (which is why dementia patients prefer to stay at home).



- Social withdrawal (the person no longer goes to choir practice, play cards or other activities).
- Misplacing items in unusual places, e.g. remote controls in the fridge.
- Putting clothes on incorrectly.
- The persons are increasingly likely to evade questions, use empty phrases or apply stonewalling tactics if they do not know the answer.
- Often they will respond irritably for no reason, be nervous or reject changes.

These symptoms can all occur at once, although that is not always the case.

#### **1.4 How is dementia diagnosed?**

By visiting a GP (the family caregiver should suggest an appointment):

- Establishment of the patient's history (anamnesis) by asking the person and his family members questions
- Laboratory tests (blood and urine)
- Test to check the memory function
- Referral to a neurologist
- Other assessments (tests, questionnaires)
- Imaging procedures for the brain (MRI, CT)
- Electrical mapping of the brain (ECG)
- Visit to a memory clinic or other institutions
- that are specialised in the diagnosis of dementia

#### **1.5 How does dementia progress?**

The disease may progress in very different ways, depending on the cause.

It is usually divided into three stages:

Stage 1/early stage/slight dementia

- Occasional forgetfulness; short-term memory loss
- Very strong feelings of loss, uncertainty, fear and shame.
- The persons are still able to live alone
- They notice that something is wrong, retreat behind a mask and revert to old strategies.
- Judgement and hygiene are still intact, but social activities and work are significantly affected.

Stage 2/mid stage/moderate dementia

- Progressive loss of mental faculties; increasing forgetfulness
- Independent life management is limited; a certain degree of supervision is necessary
- Personal hygiene is neglected
- Disorientation (time and place)
- Speech disorders (especially the ability to understand spoken language)
- Delusions (e.g. of being robbed)



Stage 3/late stage/severe dementia

- Independent life management is no longer possible
- Loss of everyday competency with complete dependence on care
- Reliant on constant supervision and assistance
- Severe memory loss and loss of language
- Family members are no longer recognised; complete disorientation
- Difficulty swallowing, incontinence (inability to retain urine and stools)
- Patients become bedridden

The character and emotions of dementia patients remain preserved throughout the course of the illness.

#### **1.6 Which treatment methods are available?**

Firstly there are medicinal treatments to slow down the progression of the disease, although they are unable to stop it permanently. Then there are other medicines that alleviate certain symptoms like anxiety, fear and delusions.

The effectiveness of each medicine differs significantly from person to person! First of all, it is important to try and positively influence the patient's behaviour without prescribing medicine. It is essential that family members learn about the condition to avoid unrealistic expectations. Family members must learn to live with the disease and to accept the dementia patients as they are. Affection, activation, occupation and empathy make life easier for the patients as well as their family members.

#### **1.7 Is dementia curable?**

Dementia is not curable, apart from a few exceptions (secondary dementia as described earlier). Certain medicines are available, but they can only slow down the degenerative processes.

#### **1.8 Do people die of dementia?**

Dementia patients frequently die of a secondary condition (e.g. pneumonia caused by their bedridden state and a weakened immune system).

#### **1.9 Can I prevent dementia?**

There is no vaccination against dementia. But a healthy lifestyle can reduce the risk of the disease developing:

- Mental activity
- Physical exercise
- Sociability
- Balanced diet with lots of fruit and vegetables
- Early treatment of risk diseases like hypertension, cardiac arrhythmia or diabetes mellitus

#### **1.10 What is particularly important?**

Learn about the disease and accept help! Caring for dementia patients is only possible if the load is shared.



## 2 General burdens in home care

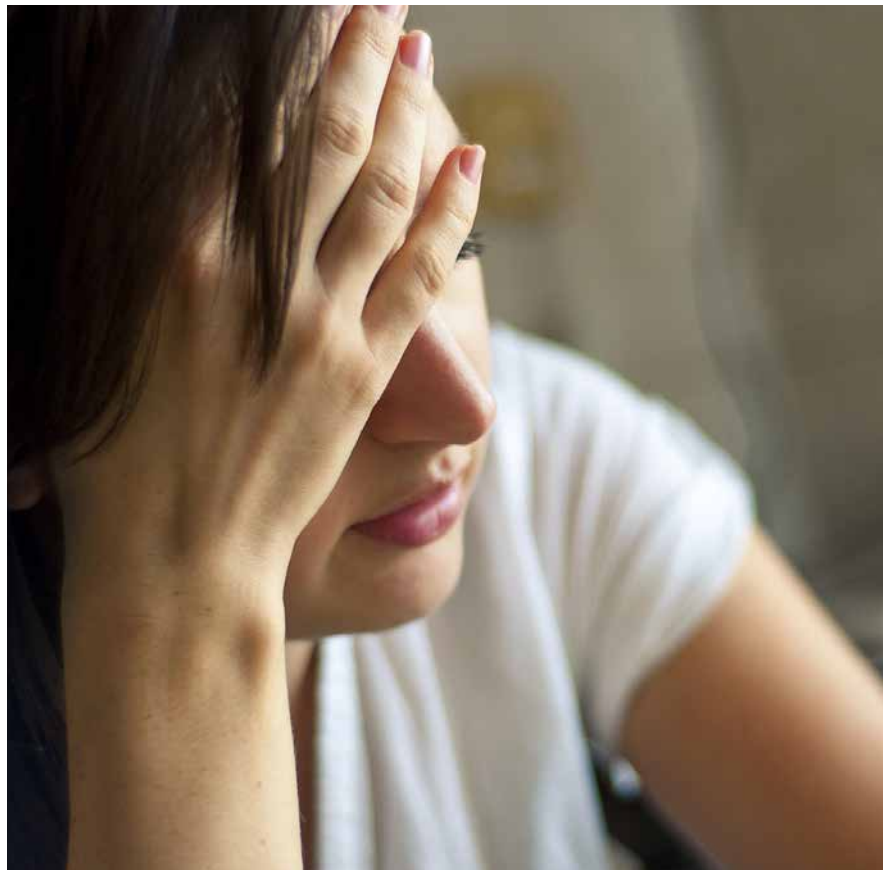


Photo: ©fotolia.com/Andrzej Wilusz

Caring for and supporting people in need is a huge challenge, but one that is accepted by family members nonetheless. Many embark on this difficult journey without knowing what to expect: They stumble into a new life situation, but have not considered what it entails. Many family caregivers for dementia patients face this or a similar predicament and suddenly find themselves thrust into a position of significant responsibility. They realise very quickly that they will have to bid farewell to the plans they had made for a life together. Merely accepting this fact is very difficult for many family caregivers.

Exacerbating their situation is the need for everyday nursing skills that very few family members possess. Tenacious 'learning by doing' is the only way to cope with their new life circumstances. Often this leads to unnecessary physical and emotional stress, sometimes even accidents. The severity of the symptoms associated with dementia patients places family caregivers in a particularly difficult situation that may burden them unduly in a variety of ways.



As time goes by, they will have to spend more and more time with the patient. They need to be there for their family member round the clock and rarely have time for themselves. They are always 'on call' and can never switch off, which can make them feel trapped and in many cases lead to social isolation.

This is why caregivers must prepare for the task at hand and factor in time to look after themselves. To do this, they need to know which burdens will arise and be aware of how they can be prevented, mitigated or removed. Caring for a family member comes with many different types of burden. They can be social, financial, physical or mental and will certainly affect their available time. The burdens differ from person to person and can occur individually or cause and influence each other.

**Social burdens:**

- Changes in life planning
- Adjusting to a new situation
- Family conflicts and relationship problems
- Bureaucratic obstacles
- Lack of appreciation

**Financial burdens:**

- Restricted personal life, altered home environment
- Integration of social services
- Reconciliation with working life

**Time constraints:**

- Increased availability is necessary
- On call 24/7

**Physical burdens:**

- Lack of knowledge about caregiving techniques ("learning by doing")
- Lifting and carrying (instead of movement)
- No work organisation (so unnecessary chores and errands)
- Lack of sleep

**Mental burdens:**

- Feelings of blame, guilty conscience
- Uncertainties
- Changes in the familiar person
- Fears, concerns, isolation
- Confrontation with disease and death

People can quickly become overwhelmed when they are forced to cope with many burdens all at once!



Symptoms of being overwhelmed:

- Irritability, impatience
- Aggressive thoughts and feelings
- Exhaustion, fears
- Insomnia
- Weak immune system
- Depression
- Pain
- Back pain, joint pain and headaches
- Heart trouble and stomach complaints
- Hypertension



### 3 Build your own network



Photo: ©Unfallkasse NRW

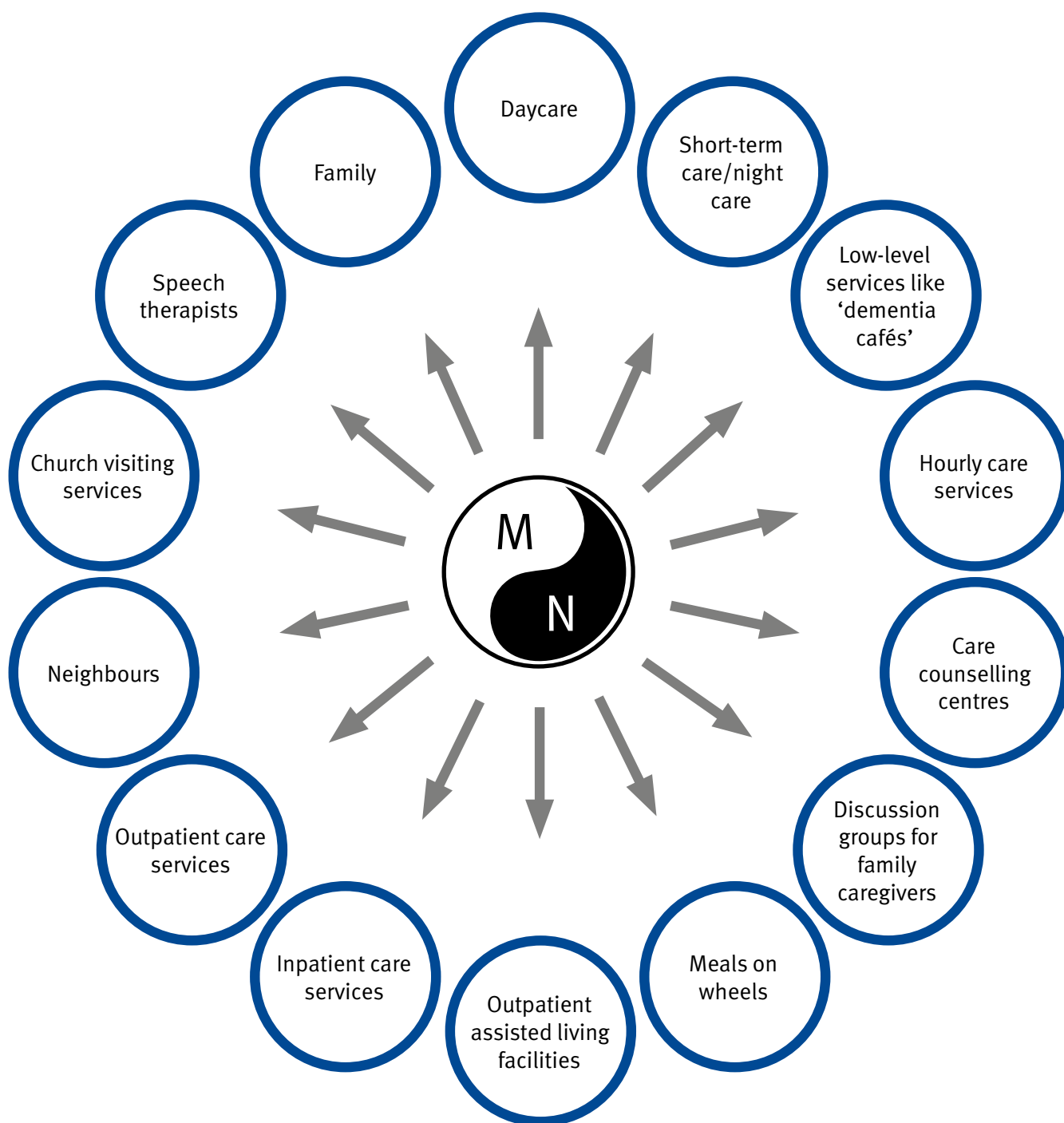


This symbol always stands for “My personal network”.

You need good organisation and detailed information to cope with the burdens of caring for and supporting a dementia patient. This is why it is so essential to build a network for care and support in your home setting.

Networks like this bring clarity to the question of which institutions and who you can rely on additionally to obtain support and relief. Talking and cooperating with the individual institutions and people (family, friends, neighbours and counselling centres) can be used as a source of detailed information, opportunities and ideas that you would not have been able to draw on by yourself or you were not aware of.







A network should always include the following institutions:

- Care counselling centres (detailed information and advice)
- Care course providers (organisation, information, care techniques and an opportunity to share experience)
- Relief services/family, friends and neighbours (provide relief, free time)
- Measures to improve your wellbeing (relaxation courses, water gymnastics, massages, back exercises, meeting friends etc.)

The care counselling centre should be a fixed point in your network, as you can go there to discuss domestic care and assistance for the needy person with somebody who is expert in this field. The staff at the care counselling centre can help you determine how to move forward and what should be important to you next.

Relief services are indispensable to ensure good planning and organisation of domestic care; they give you the space you need to take care of your own well-being. They should be available quickly and flexibly close to your home.

It is equally essential to include family, friends and neighbours, as these groups can help you to plan necessary breaks for yourself. This way you can attend a relaxation or sports course, pick up a forgotten hobby or other things.

Completing care courses is important to acquire greater care expertise, to obtain information and to learn techniques that will help you to remain healthy as well. Your personal network will make you far more confident at providing care and support, because you will always have someone to talk to when you reach a dead end. You will no longer be responsible for everything 'on your own'!

Tasks and responsibilities can be shared!



## 4 Looking after yourself



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Plan time to look after yourself from the beginning. This means that you must attend to your own needs as well, as soon as you start caring for a relative. Looking after yourself includes your emotional, mental and physical health and will help you to stay balanced. Only then will you feel at peace with yourself and be efficient.

Looking after yourself means something different to everyone and is therefore achieved in a variety of ways. So it is always entirely personal. It depends on the needs of the individual and is related to their life situation, age and health.

Various services and activities can help you look after yourself.

- Relaxation courses, fitness courses
- Regular pursuit of a hobby
- Regular meetings with friends



Looking after ourselves is something we often neglect! It's always put at the bottom of the list. We postpone it until later, tomorrow, next week! What remains? Often we forget completely that we even wanted to do something nice for ourselves! That's why it is so essential to set fixed times to take care of yourself. It will improve your ability to cope with burdens or to prevent them from occurring at all.

How to look after yourself:

- Set boundaries – learn to say “no”
- Good time management
- Include support services and other helpers in your plans
- Be mindful of your own needs
- Take regular breaks
- Relax regularly
- Maintain social contact
- Include complete downtime in your schedule (holidays)

You should practice an activating care strategy (include the patient; allow them to do things that they can still manage, even if it takes longer or they require instruction). Manage your new everyday tasks, but without forgetting your own needs!

Everything needs good organisation, which is why it is wise to prepare a daily/weekly schedule (as a chart) in which you can add daily routines, as well as time to look after yourself. It is also important to include a separate column for support services and other helpers (e.g. family members, neighbours and volunteers), because this way you can spread the burden among several other people who you can rely on. Nobody should be made to feel compelled, but the support needs to be dependable. This way you can ease the strain in many ways or even prevent the burdens from occurring.

Clarify the basics before accepting the role of caregiver:

- Why do I want to be the caregiver?
- For how long do I believe that I will provide care?
- In which domestic setting can care and support be provided?
- I'll convene the 'family council' to discuss how to organise care.
- I'll make an appointment for care counselling!
- Have I attended a care course?
- What must I consider before providing care and support to a person in need?
- How do I create a structured daily routine?

These and other questions are dealt with in detail in the brochure “Practical Guides to Care in a Home Setting” brochure. A copy can be ordered from Unfallkasse NRW.





Here's an example of what it could look like:

Mrs Mayer's life has changed in many ways since the doctor diagnosed her husband with dementia. It was a huge shock for the whole family, but it was clear to everyone that Mr Mayer would be cared for at home. Everything went quite smoothly for the first two years, although Mr Mayer gradually needed more attention and was progressively losing his own faculties. From then on, every aspect of daily life revolved around supporting and caring for Mr Mayer.

Now Mrs Mayer spends all her time looking after her husband. She has trouble sleeping, as her husband is very restless at night and often wakes her with shouts or screams. Mrs Mayer shoulders the entire responsibility of supporting and caring for her husband. Her daughter lives in Munich and visits her parents very sporadically. But during her most recent visit, the daughter did notice that her mother was looking worn out and that her father's health seemed to have deteriorated even more.

Mrs Mayer never even considered placing her husband in a care home. "We love and support each other, just like we vowed before God – in good times and in bad", she says to her daughter when she mentions that it would be possible to find a place for father in a care home. "No! I'll manage!"

She looks after everything very assiduously. It all seems easy in the beginning. But she also notices how looking after her husband, caring for him, becomes increasingly difficult over time and that she is no longer managing everything on her own. That's why she follows her daughter's advice to call in an outside caregiver who comes to support her in the morning and evening. Mrs Mayer is responsible for her husband for the rest of the day and during the night.



After a while she notices that she still needs a lot of time for care and support and that she can no longer leave her husband alone at home, even with the additional assistance of the caregiver. So she stops going to meet her friends for coffee, although the group has existed for years, and she no longer attends her aerobics class, although it “always does her good.” After all, she needs the time for her husband and cannot leave him by himself.

Visits by her girlfriends become increasingly rare as well. Mrs Mayer believes it is because her friends no longer feel at ease in her home, that they are uncomfortable paying her a visit. Perhaps it reminds them that something similar could happen to them. Apart from that, she never has anything new to talk about. Everything in her life happens at home and is always about her husband. And it’s hardly a treat for her friends if her husband shouts out for her or parades round the living room in his underpants. Things like that can be a little uncomfortable.

So Mrs Mayer spends even more time looking after her husband, because no one ever drops by for a visit, apart from her daughter who visits a few times a year and the caregiver. As a result, her thoughts are increasingly focused on the needs of her husband.

What can Mrs Mayer do? Mrs Mayer could sit down with a care consultant to plan the care situation at home. This plan must also include things that she can do to look after herself. Mrs Mayer’s age, life situation, interests, needs and health all need to be considered during planning. In the end, Mrs Mayer would have a daily/weekly schedule that she can use as a basis during the initial period.

The daily or weekly schedule orders and structures activities that Mrs Mayer must do for her husband and around the house. But between these activities, it also sets aside time that she can use for herself. It would be wise in Mrs Mayer’s case to obtain more professional assistance, to promote social contacts and to include relaxation courses.

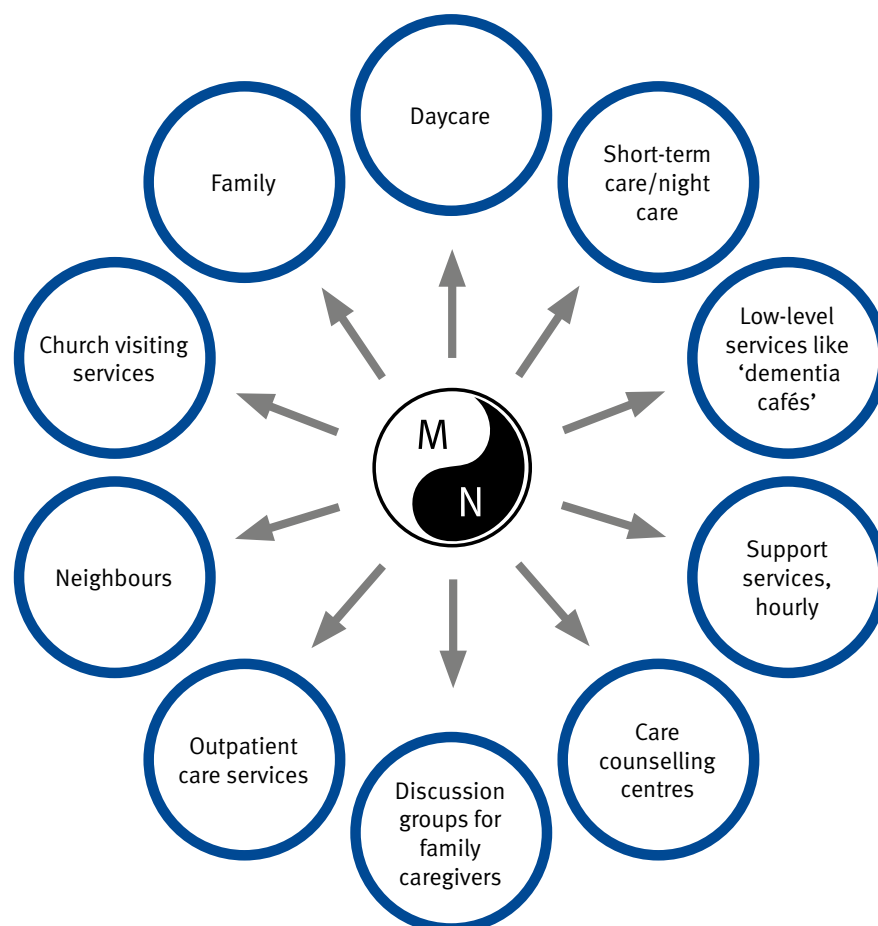
Using daycare services, visiting a dementia group or obtaining hourly respite care would allow Mrs Mayer to meet with a friend or attend a relaxation course. The current external caregiver can provide additional nursing services.

There are numerous ways to help Mrs Mayer. That’s why it is wise to visit a care counselling centre to receive detailed advice. Many people caring for family members are in a similar situation to Mrs Mayer. Increasingly they discover that they need to plan more time to support and look after a family member. But while doing everything they can to make his life easier, they often neglect themselves.

Besides the structured daily schedule, Mrs Mayer and the care consultant put together her personal network. It helps Mrs Mayer to understand which institutions can help and who she can rely on additionally to obtain support and relief.



Here's what Mrs Mayer's personal network could look like





## 5 Emotional burdens



Photo: ©fotolia.com/drubig-photo

When things get too much, family caregivers have an immediate tendency to think that they have failed. They believe that the sense of being overwhelmed comes from the practical tasks like caring at home and the time this requires. But often that's a misconception, and the actual cause of the problem is the emotional burden.

Family caregivers are influenced by moral perceptions and the expectations of family members, neighbours and society when deciding to accept the job of caring for a relative. Out of a sense of responsibility and influenced by external expectations, family members often agree to care for a relative, although they would prefer to politely decline. They suppress their misgivings, which means that they more or less stumble into the role of caregiver.

And now everything is different – the relationship becomes unilateral, and the caregiver is only there to look after the patient. Many of the tasks that the patient used to take charge of now fall to the caregiver. Not only is this a role reversal, the caregiver has to assume additional responsibilities as well.



Here's what it often looks like when a wife takes care of her husband: Until then the husband had dealt with certain tasks (e.g. gardening, repairs, disposal); but now the wife has all of this on her plate, besides looking after her husband and keeping him in check. She has to make all of the decisions and become familiar with many new areas, for instance bank business and DIY around the house. Her fear of making mistakes or not coping with everyday life merely compounds the issue.

The role reversal is equally difficult when the children become the family caregivers: They are used to their parents being there for them, giving advice and assistance, protecting and encouraging them. Now it's the other way round, and the children carry the responsibility. Many are scared of making the wrong decisions and of not being up to the task as caregivers.

And being a caregiver just gets more time-consuming and difficult as the illness progresses. It's simply the nature of the disease; the condition of dementia patients deteriorates increasingly in all areas of life, and the family caregivers are forced to watch helplessly as the illness inexorably takes its toll. Witnessing this is painful and frightens the caregivers. They need to invest more and more time and effort as the patient's condition gradually worsens. And all the while the caregivers have their own lives with all their tasks and duties that they still must fulfil. This can quickly turn a burden into an overwhelming emotional situation.

Symptoms of being emotionally overwhelmed:

- Constant fatigue, listlessness, tiredness
- Agitation, nervousness
- Depressive mood swings
- A sense of defeat and an inner void
- A sense of futility
- A sense of being worthless
- Depression
- Feelings of guilt
- Irritability, aggression
- Fear, anger, distress, grief
- Gastrointestinal complaints
- Headaches and back pain
- Weak immune system, e.g. frequent infections
- Skin conditions
- Sleep disorders, insomnia, difficulties falling asleep, sleep-maintenance insomnia, a leaden feeling in all limbs ('heavy legs')



These symptoms may occur individually or together. What counts is that you visit your doctor if you notice them developing. Discuss with your doctor what you need to do next. The most frequent symptoms of being emotionally overwhelmed are:

- Anger and fear
- Feelings of blame and a guilty conscience
- Fear of loss and grief
- Wanting to be alone
- Prescription drug and alcohol abuse
- Depression

What can I do?

- From the beginning of a care situation, you should include time for yourself as described in the chapter “Looking after yourself” and learn to accept help. The first thing you should do when you feel emotionally overwhelmed – at this point at the latest – is to create space to relax and to call on assistance.

Professional services:

- Day and night care (partially institutional form of care in which the patient receives care outside of their home for several days or nights)
- 24-hour care (a nurse provides care and support in a home setting for 24 hours per day).
- Night care (a caregiver comes to the home at night to provide care and support).
- Short-term care (the person with dementia is admitted for inpatient treatment lasting several days, e.g. when the caregiver goes on holiday or a respite break; short-term care is also a useful alternative if the caregiver becomes ill or experiences a crisis situation).
- Volunteers (occupy the dementia patient by reading aloud to them or taking them on a walk; they do not carry out any nursing tasks)
- Respite for family caregivers (increasing numbers of respite providers are offering programmes for people caring for relatives). Discuss the option to apply for respite at a health retreat with your GP.
- Holidays with the patient (holiday packages for caregivers with dementia patients are becoming increasingly common. What makes them special is that although you go on the holiday together, each person has enough space for themselves).
- Relief through talking
- Meetings for caregivers
- Café meeting points
- Self-help groups
- Pastoral care (talk to the church social worker or minister).
- Telephone crisis lines
- Discuss whether you might need a course of psychotherapy with your GP. It's good to get things off your chest.
- Relief by calling on care counselling centres



Care support centres:

- Municipal dementia service centres, welfare associations, health insurers and private sector providers
- Relief through training
- Care courses (they are offered by health insurers, welfare associations, family education centres and private sector providers; the costs are covered by the care insurance providers).
- Courses on dealing with dementia patients (they are offered at dementia service centres; the costs are covered by the care insurance providers).
- Relief through relaxation courses
- Autogenic training
- Progressive muscle relaxation
- Feldenkrais
- Yoga
- Breathing exercises
- Meditation
- Sounder Sleep System

Things you can do every day:

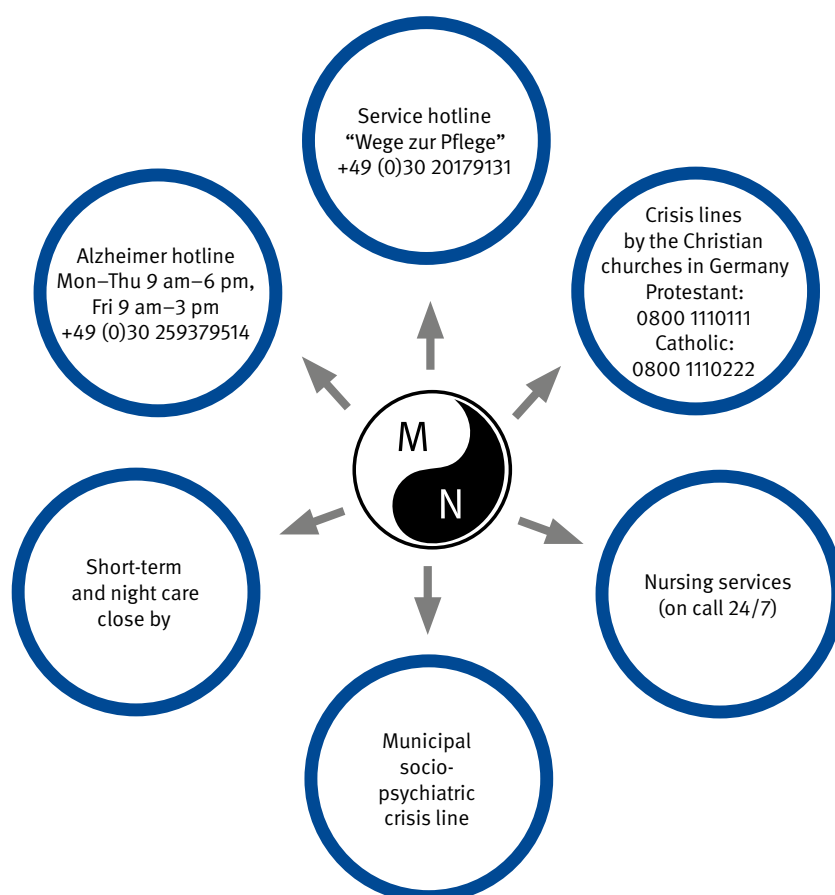
- Be mindful of your needs and create islands in your everyday routines
- Consciously take time for yourself
- Read a book
- Enjoy a leisurely cup of coffee
- Meet with a friend
- Talk with a friend on the phone
- Consciously absorb the beauty of nature etc.

As you can see, there are plenty of things that can ease the burden and help you stay healthy. Now find out what you enjoy most. Experiment with a variety of relaxation techniques to discover the course that suits your needs. The care consultants near your home will gladly help to pick the best services for you.

It is good to find out what is available for emergency situations and to assemble a network of helpers. Perhaps you can make contact with a few institutions beforehand and take a look around their facilities.



### Institutions that can help in emergency situations



### Case example:

Mrs Mertens was 77 years old. She had her own small apartment. Her only daughter also lived in the same city with her family. Mrs Mertens' husband passed away five years ago. Until six months ago, Mrs Mertens had been completely independent. She sang in a choir and was a member of a handicrafts group. She also paid charitable visits to the residents of an old folks' home and was popular with her neighbours.

But slowly she started to change. All of a sudden she stopped going to choir practice. "I've done that long enough now, and I don't want to learn all these modern songs anyway." She no longer turned up regularly at the care home or her handicrafts group. Neighbours hardly ever bumped into her in the street. When her daughter paid her a visit and asked what was happening, her response was initially fierce: "That's my business ..."

One day her daughter received a call from the police. The officer enquired whether Mrs Mertens is her mother. Apparently she was found walking down a main road, unable to find her way home. She was taken to hospital, said the officer! The daughter, her husband and the children (aged 7 and 17) realised straight away: "Something isn't right here."



A diagnosis was made at the hospital: Mrs Mertens is suffering from dementia! The family was invited in for a consultation, and it became clear that Mrs Mertens would not be able to return to her apartment alone. She was initially moved to the geriatric ward and then, after three weeks, the daughter took her mother into her home. Mrs Mertens moved into two rooms – a small living room and a bedroom with en-suite bathroom. A nursing care application was filed with the care insurers, and Mrs Mertens received approval for Care Level 1 as a person requiring significant assistance.

Looking back, her daughter says: “Things were terrible in the beginning. I wanted to look after my mother – she had always been so caring to me. But I could never do anything right in her eyes, and there was just endless paperwork as well! Thankfully I received help from the nurse at the transitional support centre in the hospital. Then we had to clear out mother’s apartment – all the furniture was brought to our home. I was really irritable. I wanted to manage everything. I would berate my husband and the kids, but then I felt guilty and was constantly in tears.

Mother became increasingly exhausting as well. She paced around the house like a caged tiger, wanted to help, but just created chaos. Our youngest daughter was the only person she seemed to connect with. She always called her Hedwig, the name of her younger sister. But she’s been dead a long time. I kept reminding her that, but we would only end up arguing. Our daughter was less bothered. She would laugh and say: “Now I’ve got two names!” As time went by, I noticed that Hedwig was really important in my mother’s life. She was a gateway to her own childhood and brought back memories. Hedwig symbolised trust and certainty. Last year I was thrilled when she called me Hedwig as well!

The care counselling centre in town was a real blessing for me and my family. My neighbour told me about it when she found me weeping at the bottom of the garden one day. Suddenly I felt understood, and the staff helped me to find the support we needed. I learned that I do not have to manage everything alone, that it is better for us all if I accept help. So gradually I started to cope with everyday life.

I found the courage to talk with my brother and sister, to arrange fixed afternoons when they look after mother. Then I started taking her to the daycare centre for one day per week. Mother was somewhat reluctant at first, but once she had realised that she would be picked up and brought home, she started to enjoy it. That put my mind to rest as well. I felt comfortable.

A nurse now comes to wash mother on two mornings each week. I help her the other mornings, and by now we’ve established a routine. Every fortnight, mother goes to the parish centre for a few hours in the afternoon. The congregation there has set up a care café for people with dementia. She really enjoys that. And I’m astonished to see that she frequently recognises the other visitors.

My neighbour and I go to a discussion group for family caregivers. I’ve been attending the meetings for eight months now. I find it so helpful to realise that I am not alone with my problems, and handing the responsibility to other people from time to time eases the burden as well. I feel more balanced and at ease.

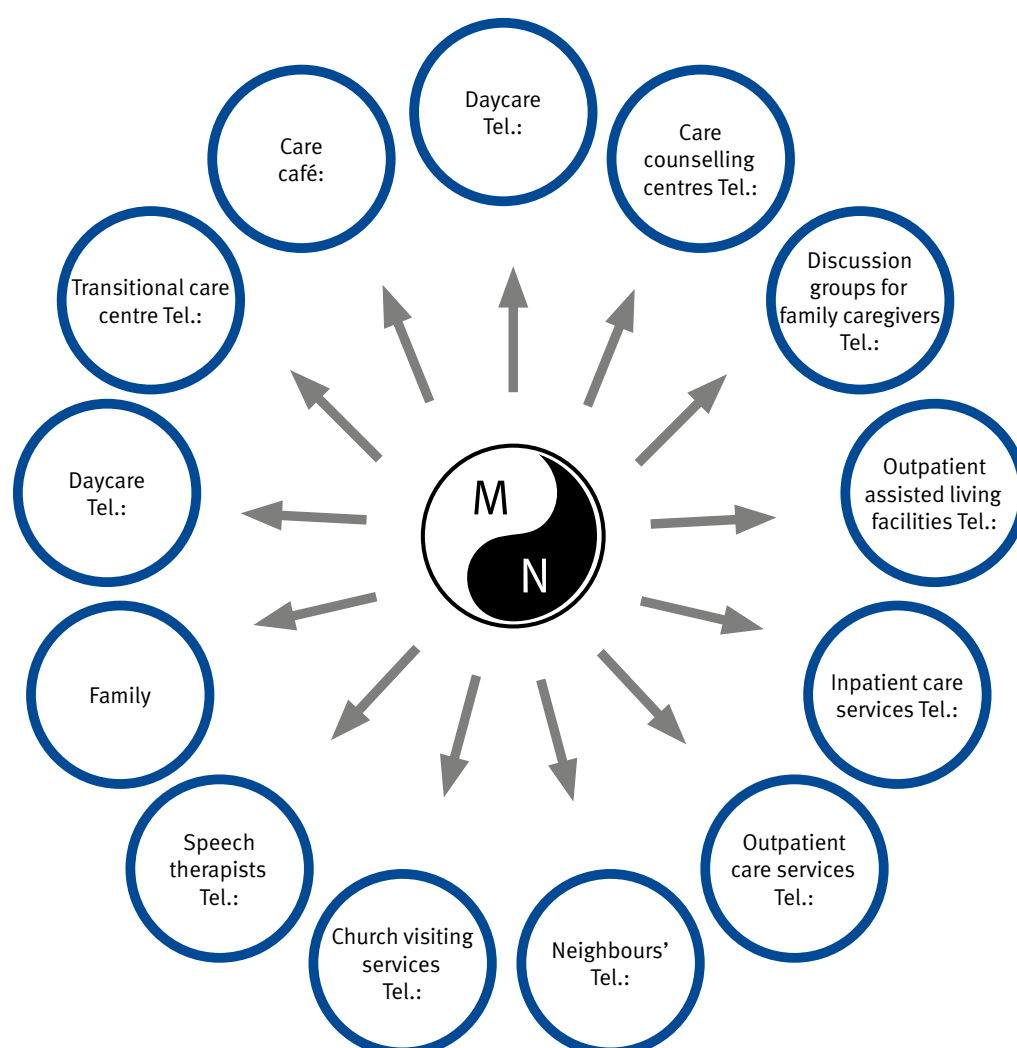


Twice per week I take mother to the daycare centre, and we have even planned a holiday. I'll put mother in short-term care while we are away. Looking after her, accompanying her, caring for her as a dementia patient is an immense challenge. I only managed because I have learned that I do not have to do everything by myself, that I can delegate responsibility from time to time.

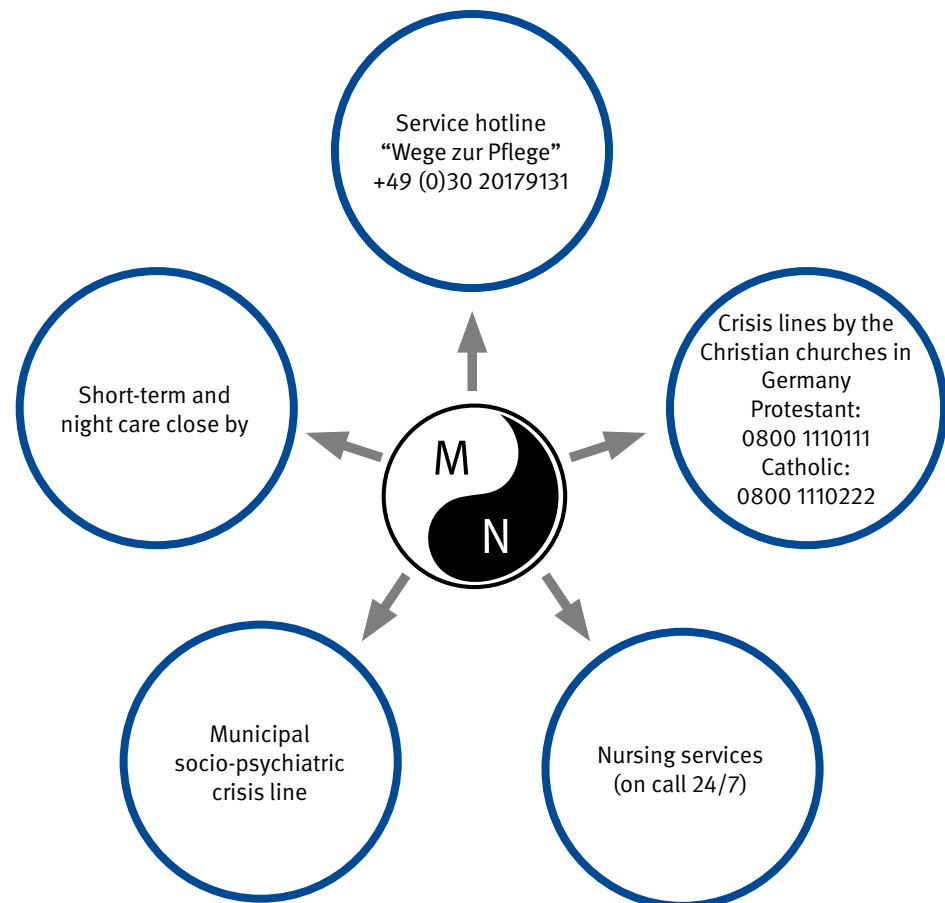
I have also understood how essential it is to receive professional advice and to call on the assistance of nursing and support services in good time. I also know that I have to establish and build my own network to ease the burden and to be there in emergencies.

#### **“Mrs Mertens’s Personal Network” for care and support**

#### **“Mrs Mertens’s Personal Network” for when she reaches the end of her tether!**



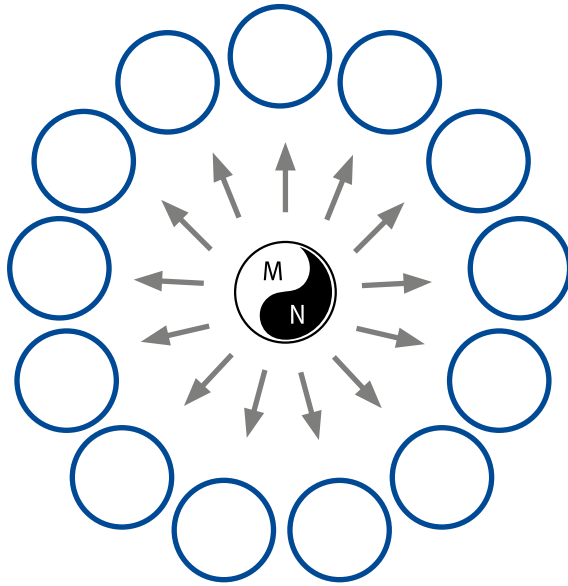






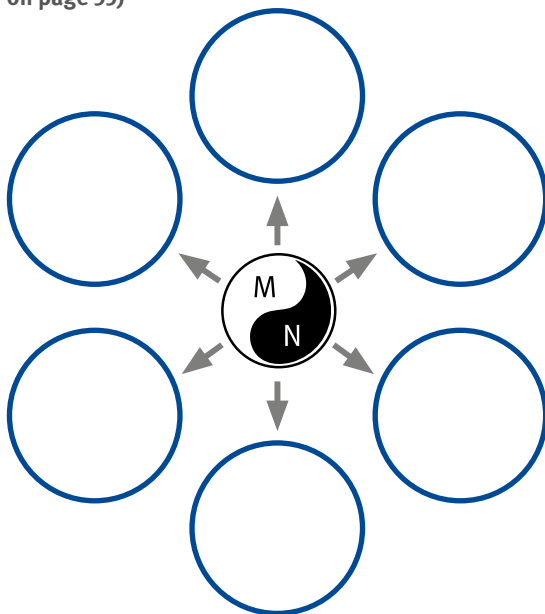
## 6 Put together your own network here!

**“My Personal Network” for care and support**  
(copy template on page 54)



Use the template to add the names of support institutions, their phone numbers, contact persons and opening hours. Also write down the names and telephone numbers of relations, friends, neighbours and acquaintances.

**“My Personal Network” for when I’ve reached the end of my tether** (copy template on page 55)



Use the template to add the names of support institutions, their phone numbers, contact persons and opening hours.



## 7 Tips for dealing with dementia patients



Let the patient speak:

“We will get along better if you follow these tips!”

- Learn more about me, then you will find many things easier!
- Do not make so much effort to bring variety to my day. It is easier if my day is simple and neatly structured. That’s why I should do the same things at the same times, every day.
- If I ‘just sit there’, lost in my world and my thoughts, then stop for a moment, draw closer and show me affection.
- When you speak with me, please do so calmly, quietly and in a clear voice. I won’t be afraid then.
- It helps if you look at me and touch me gently before you start to speak. That way I know when you are talking to me. Do not be sad when I forget what you said to me. It happens a lot.
- Other people often find it hard to understand me, but I have the same difficulties with them. So please be careful that your facial expression matches your voice. Otherwise I might become frightened or angry.
- I don’t always understand everything you say, but occasionally it is more than you think.



- Do not spread hecticness and stress and do not ask me to do two things at once; I become overwhelmed, which makes me uncertain or agitated.
- Do not correct me all the time, it will only make me angry.
- Let me do the things I can still manage – at least it keeps me occupied!
- And if I do become agitated, just sit quietly next to me and hold my hand. Then I will know that you are there for me and I start to feel safe.
- I love listening to my music, but unfortunately I've forgotten what it is. It helps if you know what I like and can put on a CD for me. But remember: do not leave the CD or the radio playing for too long. I might become nervous. We can sing songs together, ones we enjoyed years ago – I still know the words.
- Please serve my food from the front and let me know it is coming. That way I won't startle. If you are feeding me, do so slowly, as I might otherwise not know what you are doing and feel threatened.
- People in different cultures eat in all kinds of ways. I used to eat with a knife and fork. Now I can no longer manage. Let me eat with my fingers. There are people all over the world who do precisely that.
- Do not play-act. I'm good at telling when people are genuine. Emotional perception is not something I will lose. When I sense tension, my emotional responses can be varied, for instance sadness, anger, rage or distress.
- Remember where I hide things, then they will be easier to find.
- Let me be in your memories as I once was, and accept me for who I am now!
- Don't worry about me all the time. Remember to take care of yourself!
- Forget what other people say. Just hug me and love me instead. It makes me feel safe.



## 8 “Learn more about me, then you will find many things easier!”

Helpful things to know about my loved one, the dementia patient

Important life events	positive	negative
Childhood events		
Events during adolescence		
Family events		
Illnesses		
Global events (war, displacement, imprisonment)		
Places of residence		
Preferences	earlier	now
Dislikes		
Habits		
Skills, gifts (practical, arts/crafts, languages)	earlier	now
Hobbies	earlier	now
Profession		



## 9 A guide to a fruitful conversation



Photo: ©fotolia.com/bilderstoecken

- As a rule, approach your dependent family member from the front (remember that the field of vision becomes narrower later in life).
- Move down to the same level and establish eye contact. Then pause briefly.
- Give your family member a moment to become properly aware of your presence.
- Address your family member by name.
- Speak slowly, calmly and clearly.
- Use gestures and touch to support what you are saying.
- Speak in short and simple sentences using familiar words.
- Only communicate one piece of information or news at a time.
- Only ask one question at a time.
- Avoid discussing topics objectively.
- Suggest things if your family member is having difficulty deciding.

### Validation – a special kind of conversation

Validation is a good method to use when talking with family members who suffer from dementia. Validation is like appreciation, and in this case means that you take and appreciate what has been said by your family member as good and valid. It does not mean that you address the objective content of the statement, rather that you acknowledge the emotion 'behind' what is said.



Here's an example: When your family member says over breakfast that he would like to go home, it is not advisable to respond to the objective content (probably the house no longer exists or he has not lived there in 50 years). Try to look 'behind' the statement itself. What is the underlying emotion? Is he feeling lonely? Is he looking for comfort? Is he uncertain? Try and respond from that perspective: "Do you feel lonely? Are you missing your home?" By responding this way, you show your family member that you take them seriously. He will feel understood, which creates a bond of trust. He will not feel humiliated by the statement: "This is your home, right here! Where else do you want to go?"

Another example is when the dementia patient is again hunting for something and accuses you of having stolen it. What is 'behind' the statement? Perhaps mistrust, distress or fear? In this case as well, it is better for everyone involved to avoid addressing the objective content. Try to bring your family member back down to Earth by mirroring their behaviour. "Do you feel betrayed? You're angry! Are you maybe just getting yourself all worked up?"

Managing conversations this way is neither a magic formula nor a therapy! But it eases the pressure that both sides are probably feeling. Discussing things objectively with dementia patients will usually leave both sides feeling frustrated and misunderstood. Validation is unlikely to work all the time – we are human, after all – but it is certainly worth a shot.

For other examples and background information, visit:  
[www.integrative-validation.de](http://www.integrative-validation.de)



## 10 Dementia – In the depths of forgetfulness



A. Daldrup/Unfallkasse NRW

Gentle billows, moving teal  
in tenderly twisted times.  
Chasing after the lost ideal,  
lonesome pages, ringing chimes.

One last time life is drifting past  
in all its gruesome ordeal.  
A vision of Thebes, a shadow cast,  
where heathens in the gloomy city kneel.

A tight feeling in my chest,  
the forbidden callous scheme.  
Eternal spirit, delusive dream,  
and a slight touch of distress.

Understand. Understand, my dear!

Deserted, sore and left behind,  
warmth alone my heart cannot abstain.  
I'm begging you, masses, men and humankind  
only love alleviates my dreadful pain.

A twinkle, a glitter of the truth,  
my home, return to me!  
So familiar and pure, my forlorn youth,  
I drown my sorrows in thee.

C'mon, c'mon! Hurry, let's go!  
Alas, did you forget?!

When I see them playing  
before the ancient arbour,  
I lose myself, I'm swaying,  
your arms must be my harbour.

Woe is me! How badly off am I?!

A begging for love,  
misunderstood,  
lonely souls amid the never-ending  
waste land.

Tim Daldrup



## 11 Practical guides

### 11.1 Non-recognition

“Let me be in your memories what I once was, and accept me now for what I am!”



Photo: ©fotolia.com/Creativemarc

Beyond a certain point, dementia will inevitably mean that the patient no longer recognises his family members or home. It is how the disease progresses. However hard it is, you should accept your family member's illness and release them from their previous 'role' or your 'perceptions'.

You can keep all the images alive in your memories, but you should accept your family member the way they are 'now'. You should reconcile yourself with the situation. It is not always easy, but it provides the opportunity to embark on a new and easier journey. Deal with your family member as an equal. For instance, if the dementia patient no longer recognises you as his daughter, rather as his neighbour, do not discuss the issue (he would not understand it anyway). Use the moment to establish common ground instead. Embrace your family member or indulge in reminiscing shared memories. Give yourself enough time to listen and talk.



### Practical guide “Non-recognition”

What should you do when people are no longer recognised?

- The inability to recognise another person starts later if the relationship has existed for a long time.
- Do not show hurt or anger if your family member does not recognise you.
- Try to find out whether there is a particular reason why they no longer recognise you (noise, brightness).
- Stimulate memories in your family member (talk about your life together or hang up old pictures).

What should you do when your family member no longer recognises home?

- Give the dementia patient time to respond and repeat the information when necessary. Always repeat the same key words if you can.
- Communicate typical ‘home criteria’ verbally (look for key stimuli, e.g. fireplace, winged chair).
- Distract the dementia patient (using validation or shared activities like a meal).
- Show intimacy (dementia patients absorb much of their information emotionally, so give them a hug).

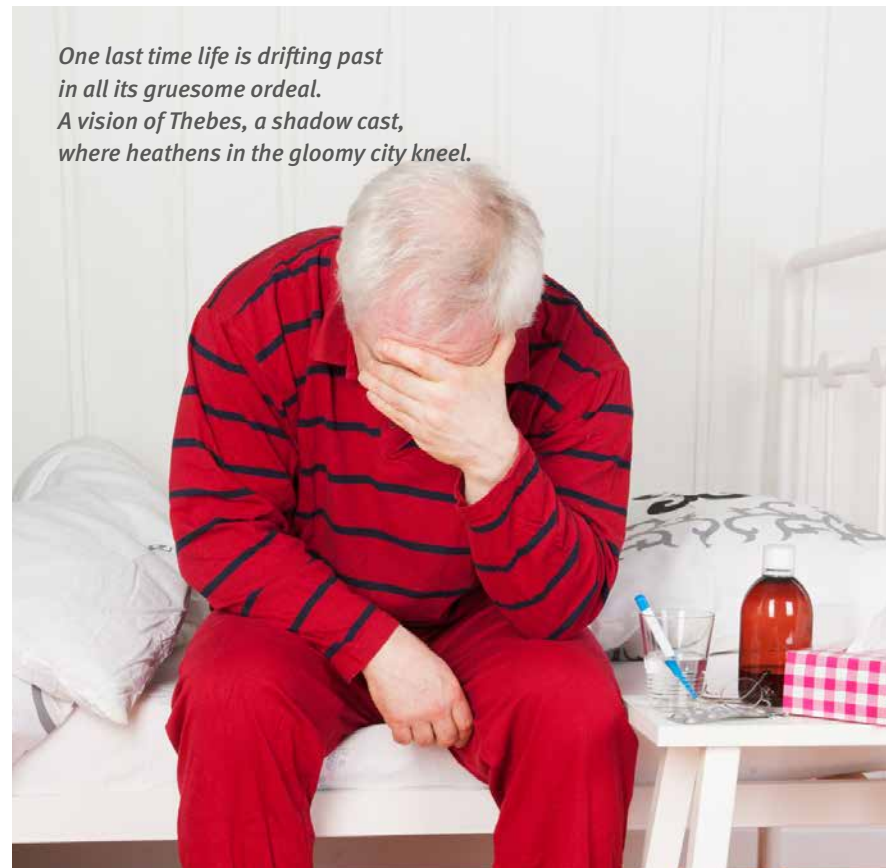
What should you do when they accuse you of things?

- Try to remain calm and relaxed.
- Offer your help.
- Do not become embroiled in objective discussions!
- Accept the situation (play along, do not take it personally).
- Make sure that everything remains safe!
- If necessary, ‘remove yourself from the situation’ or distract your family member to bring them back down to Earth.
- Get professional assistance early on (doctor, care counselling).
- Take a course in validation.



### 11.2 Disturbances in the circadian rhythm/nocturnal restlessness

“Give me a structured daily routine, and I will not disturb your sleep!”



One of the reasons for the disturbed circadian rhythm among people suffering from advanced dementia is that their brain waves slow down. This deceleration means that they feel more tired and often fall asleep during the day. These are consequences of the organic brain disorder. Because they tend to dose off and sleep during the day, the dementia patients will be less likely to sleep through the night and will experience longer periods of wakefulness, which in turn leads to tiredness and sleepiness during the day.

In addition, the circadian rhythm is controlled by a region of the brain that stimulates the secretion of melatonin when darkness falls in the evening. This helps to promote sleep, and it also regulates the soundness of sleep by means of a certain hormone. This regulatory mechanism is disturbed among dementia patients.

And they will certainly feel exhausted during the day if they experienced a restless night, especially if they got up and put on their clothes several times. This will frequently disturb the sleep of family members as well, who will then be happy if the dementia patient sleeps in the daytime. But this is a vicious cycle, as they will be more wakeful in the evening and during the night.



### Practical guide “Disturbances in the circadian rhythm”

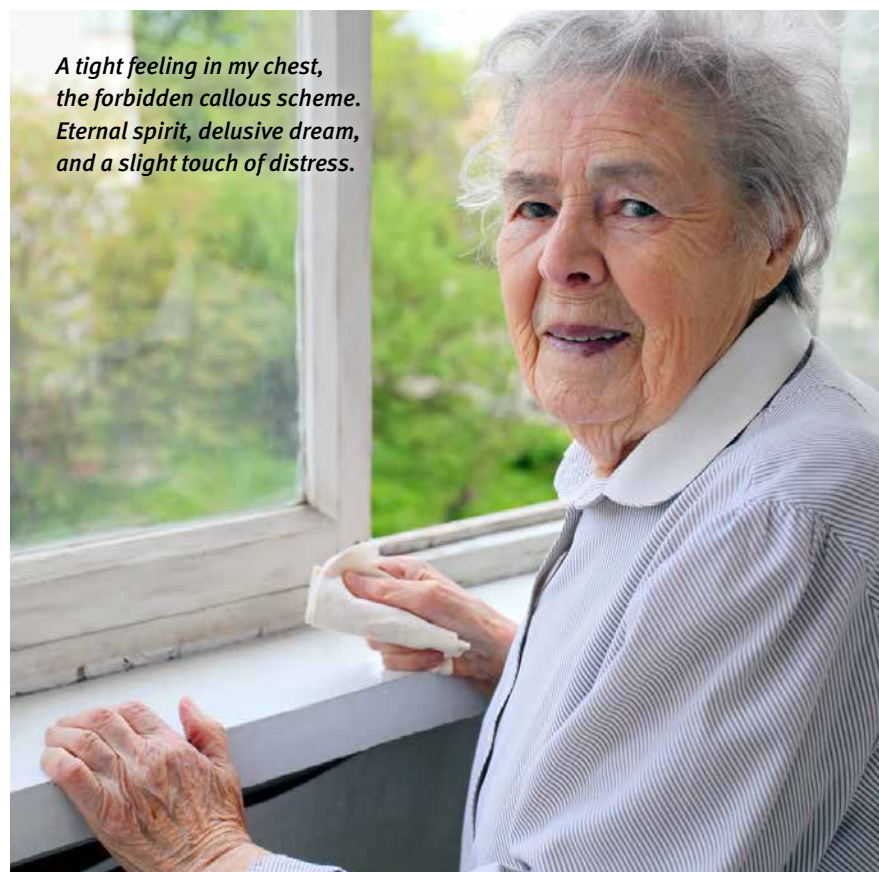
What should you do about nighttime disturbances?

- Try to keep your family member awake during the day.
- Try to find out whether there is a particular reason for them being restless at night (noise, brightness).
- Milk or herbal teas can sometimes help people sleep.
- Keeping a night light burning might be a good idea, too.
- Avoid serving large meals or drinks containing caffeine in the evening.
- Ask your doctor about medication (sometimes ‘normal’ sleeping pills can bring relief as well).
- Make sure the other person is safe if they are restless at night (lock the front door and possibly set up an area where your family member can walk about at night).
- Call on the services of a night nurse (the care insurance will cover part of the costs if your family member is assigned to a Care Level – enquire at a counselling centre).
- It is essential that you look after yourself. You simply cannot keep getting up at night. You need your sleep as well!



### 11.3 Angry, stubborn, irate and intransigent behaviour

“Do not correct me all the time, it will only make me angry!”



While these behaviours are associated with dementia, the root cause may lie elsewhere. Try to determine the triggers by taking a closer look at the dementia patient's life history (biography) to identify key experiences. In most cases they will be formative events such as experiences of war that flare up repeatedly in your family member and seem real in that moment.

So remember, the situation is actually happening for him, and it causes fear, anger, rage and other emotions. This is why it is vital to be familiar with the dementia patient's biography, to know how to respond in these instances. It will protect you as a family caregiver and help the dementia patient in a situation of need. Keeping the person occupied and active can prevent these episodes from occurring. It releases tension and brings other thoughts to mind. All the same, it is possible that the dementia patient will revert to these behaviours once again. The following practical guide helps you to know what to do when this happens.



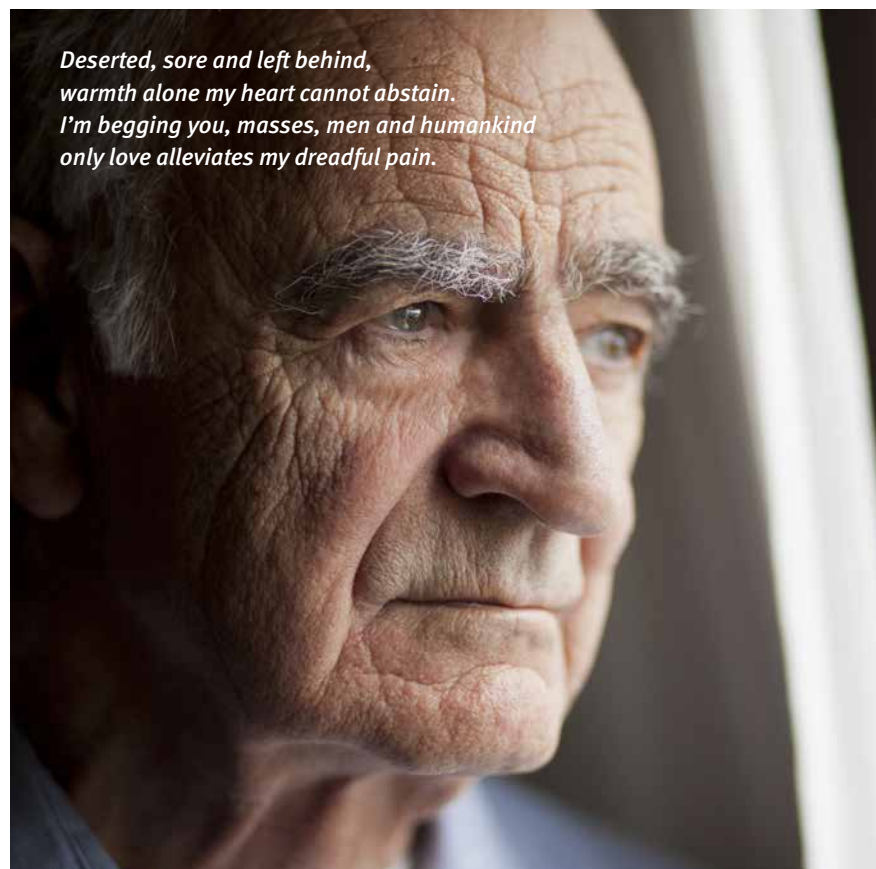
**Practical guide “Angry, stubborn, irate and intransigent behaviour”**

- Do not take accusations and insults personally!
- The more you resist, the more likely it is that the situation will get out of hand.
- Exude calm.
- Do not contradict.
- Do not raise your voice. Speak calmly.
- Address the emotions (“You are really angry/irate! No wonder”) to bring your family member back down to Earth.
- Talk about positive periods/phases in life (work/hobbies).
- Do not physically restrain the dementia patient.
- Distract him and do not mention the bone of contention (move the conversation along to something positive).
- Simply accept things you do not understand.
- Establish boundaries! (“I don’t want that!”)
- Remain safe (leave the room).
- Try to find out what triggered the behaviour; avoid these situations and/or triggers if possible.
- Ask for help at an early stage!



#### 11.4 Gradual silence, inability to engage in routine activities, apathy

“If I ‘just sit there’, lost in my world and my thoughts, then stop for a moment, draw closer and show me affection”



Severe mental degeneration may occur in late stages of dementia; speech becomes incomprehensible and might even be lost entirely (silence). The ability to cope with everyday life is lost, and bodily hygiene becomes the primary concern for family caregivers. Sequential activities are no longer possible. The joints become stiff, and many patients can no longer walk unassisted. Dementia patients can become unable to maintain even the most basic personal hygiene (urinary and faecal incontinence); they are entirely dependent and are barely able to swallow.

Care in the family will tend to become calmer during this phase – the periods in which the dementia patient was restless or agitated are over. But this does not ease the mental burden on the family caregivers, because now they will start to wonder whether they did everything right and how they should proceed from now on.



**Practical guide “Gradual silence, inability to engage in routine activities, apathy”**

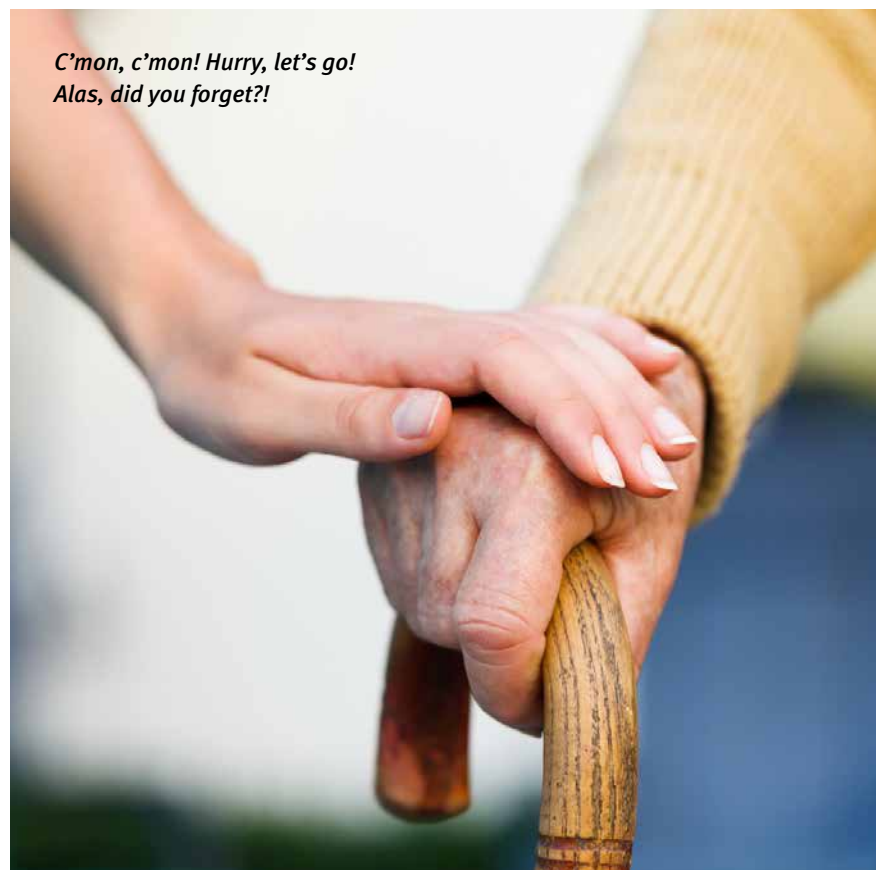
- Accept help!
- Visit a care counselling center or professional nurse to decide what you can manage yourself and where you need assistance.
- Try to accept that your family member is retreating into their own world.
- Other stimuli may become important for them, for instance different aromas; fragrant care products, the smell of food or the scent of flowers – ask yourself: what does my family member enjoy?
- From now on it is important that food is strongly flavoured (season additionally if necessary).
- Play the person’s favourite music, although it is important to alternate between acoustic stimuli and quiet.
- Reading aloud or singing is suitable.
- Always address your family member by name; talk about the old days!
- Physical contact is also important in this phase – so hold their hand or gently caress their face.

An apt description for this phase in life might be as a slow farewell or a time of letting go. Try to create beautiful moments for yourself and your family member.



### 11.5 Nervousness, increased agitation, compulsive pacing

“Let me pace. Protect yourself and me from dangers!”



Many dementia patients will experience a phase of heightened agitation, nervousness and compulsive pacing as the illness progresses. This can manifest in different ways, depending on the patient's personality and situation. Some will simply be restless, wander aimlessly or endlessly search for things. Others will run after their family members, appear agitated and keep repeating the same sentence over and over.

Family members have a hard time coping with this agitation. Compounding the issue is that the dementia patient is no longer able to appreciate risks. For instance they may walk out into a busy street, leave the house without a jacket in winter or get lost and become unable to make their way home. Dementia patients are more at risk of falling as well.



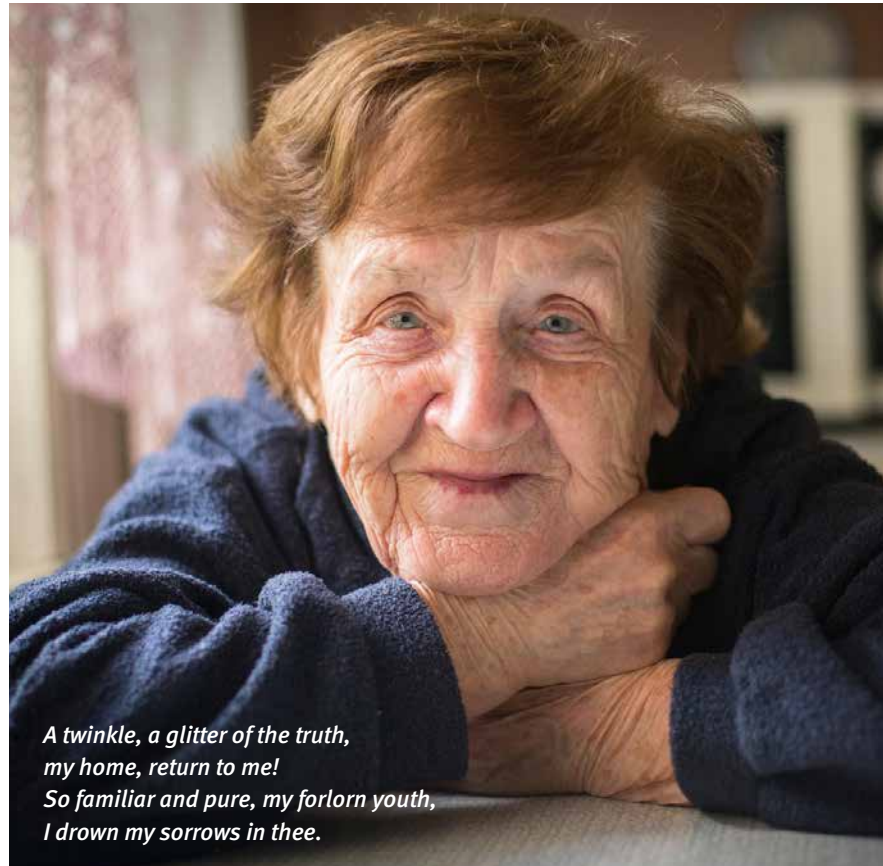
### Practical guide “Nervousness, increased agitation, compulsive pacing”

- Try to maintain the same daily structure and to spread chores over the day (e.g. folding laundry etc.).
- Find safe places for your family member to pace (exercise stimulates the secretion of happy hormones, improves the mood and eases nervousness).
- Sew your address into your family member’s clothing or put a note in his pocket. Inform your neighbours or possibly hang a curtain on the inside of the front door.
- Be prepared that your family member is quite likely to abscond.
- You might want to obtain a tracking device or another piece of equipment (ask in a medical supplies shop).
- Avoid serving drinks containing caffeine, especially in the evening.
- Make sure there is good lighting.
- Put up points of orientation (pictures, signs etc.).
- Remove tripping hazards, e.g. loose rugs.
- Make certain your family member receives enough food and drink (anxiety burns more calories, so possibly consider dietary supplements).
- Remove hazards by clearing away detergents, medication or certain plants.
- Take a close look at the side-effects of any prescribed medicine and discuss the issue with your doctor if necessary.
- Ask for help, e.g. low-level services in which care assistants go for a walk with the dementia patient.



### 11.6 Inappropriate behaviour

“I’m not doing all of this on purpose!”



There are many situations in which living with a dementia patient will be testing. The following lists examples that occur frequently.

- Inability to recognise objects: The dementia patient mistakes the wardrobe for a toilet and relieves themselves there.
- Unwarranted accusations: Family members are repeatedly accused of having stolen the person’s wallet or other items.
- Inappropriate behaviour: The dementia patient comes into the living room in their underwear and wanders around, although guests are present.
- Smearing with faeces: The dementia patient believes they are cleaning the toilet, when in fact they are smearing it with faeces.

Dementia patients do not do these things deliberately, and it is not meant personally. It is simply a result of the illness. This is why you should not take it personally. It is good to remain calm in these situations and to look for the reason or trigger.

Family caregivers can find living with a dementia patient extremely testing due to these behaviours. Nevertheless, they can rise to the challenge by obtaining information and



changing their own responses. In many cases there are things that the caregivers can do to prevent or mitigate the situations. Doing so will improve the quality of life for the dementia patients and family caregivers alike.

### Practical guides “Inappropriate behaviour”

What should you do when objects are no longer recognised?

- If necessary, explain what it is.
- Demonstrate how to use the object (pick up the brush and run it through your hair).
- Hand your family member the objects (place the brush in their hand and run it through their hair if necessary).
- Put up pictures or signs in certain rooms (bathroom, toilet).
- Install safety features on the oven and certain drawers.
- Install safety features on the power supply and sockets.
- Lock away toxic substances: Detergents, medicine, plants (e.g. cyclamen, amaryllis; visit [www.poison.org/articles/plant](http://www.poison.org/articles/plant))

What should you do if they accuse you of things?

- Accusations are often prompted by feelings like fear, loss and grief.
- Do not take it personally.
- Try to remain calm and relaxed.
- It helps to have duplicates of certain things, e.g. keys, handkerchiefs, spectacles, wallets.

What should you do about inappropriate behaviour?

- Try to identify the cause (biography).
- Encourage the dementia patient to copy your behaviour (e.g. when eating).
- Do not correct your family member unnecessarily; respect his perceptions.
- Do not argue with the dementia patient if they refuse to accept your explanation.
- Remain calm and relaxed (remove yourself from the situation: take a deep breath and count to ten!).
- Try to see the funny side: laughing together eases the tension.

What should you do about smearing faeces/incontinence?

- Perceive agitation as a warning sign.
- Accompany your family member to the toilet.
- If necessary, use resources like a body suit.



**11.7 Illusions (false perception of reality), hallucinations ('seeing things'), delusions**  
"Do not be sad if my mind leads me astray, just support me!"



The following example helps to categorise these false perceptions: When a husband suffering from dementia sees his wife and believes her to be his mother, this is an illusion. In contrast, a hallucination is when he sees his mother sitting next to him on the sofa, although he is alone. If he is convinced that strangers who come to his apartment are stealing from him, this is a delusion. These delusions are often associated with deep fears. Delusions are common in dementia.



**Practical guide “Illusions (false perception of reality), hallucinations (‘seeing things’), delusions”**

Try to explain things and remain calm your family member, without casting doubt on the truth of what they are saying. For instance, if the dementia patient calls for his mother, although she has been dead for decades, it does not help to explain to him that his mother passed away a long time ago. A better strategy is to look at what the patient may be trying to express, for example: “You are missing your mother!”; “You feel lonely!”

- Try to change the subject.
- Help to search for the lost item; remember the preferred hiding places (e.g. money in the laundry cupboard or a biscuit tin).
- Do not argue with your family member if they refuse to accept your explanation.
- ‘Playing along’ can sometimes help in certain situations (e.g. removing an apparently threatening object).
- At times it will be worthwhile to consult with a neurologist in cases of severe delusions (special medication), especially if the dementia patient is plagued by these fears.



### 11.8 Sexuality

“Forget what other people say. Just hug me and love me instead. It makes me feel safe!”

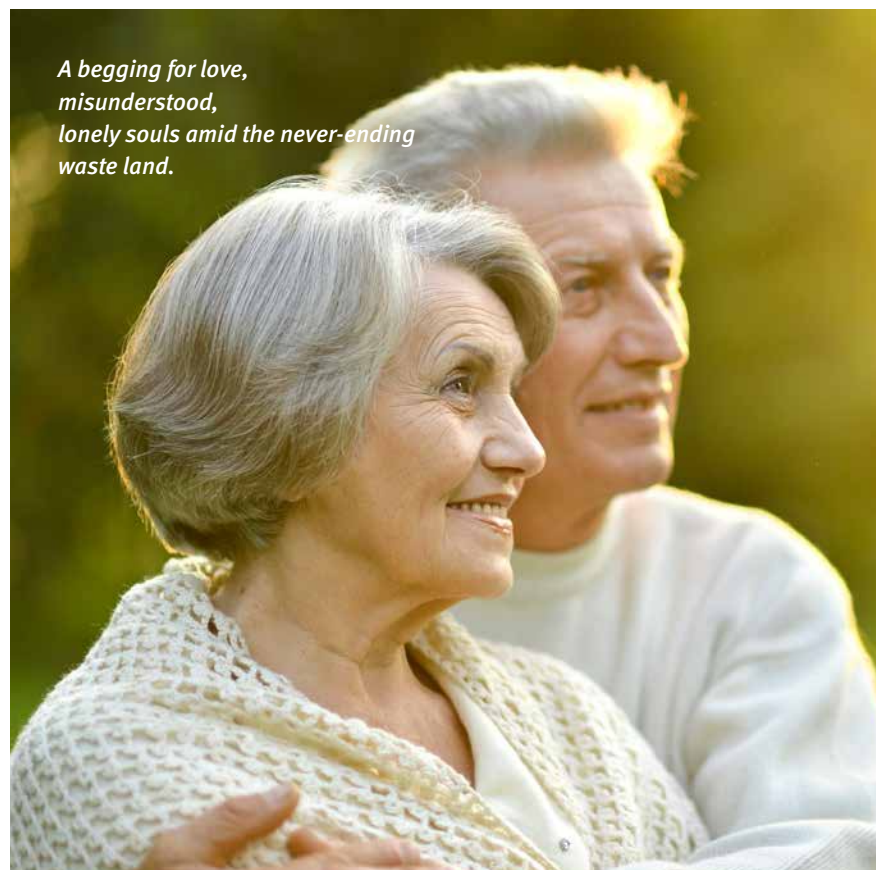


Photo: ©shutterstock.de/Ruslan Guzov

People tend to speak about sexuality in old age only behind closed doors. Sexuality in connection with dementia is an even bigger taboo and also associated with shame. But being unable to experience sexuality can be a painful loss for many family caregivers.

Many of them would like to continue a sexual relationship with their partner. But often they feel guilty (“Is it alright if I want to be intimate, or am I just being selfish?”). Our society frequently reduces sexuality to intercourse, although it has many other facets. They include the desire for closeness and affection as expressions of love and comfort. They can offer the couple stability and security in a phase of life that is otherwise full of loss and fear.

Frontotemporal dementia manifests also as sexual disinhibition accompanied by an overwhelming libido. As a result, the dementia patient will behave differently and in ways with which you are not familiar. He will be unable to control his own libido.



Here it is necessary to overcome moral inhibitions if it is good for both partners; but it is equally important to set boundaries if the sex drive of either the dementia patient or their partner becomes a burden. As soon as either of them needs to ‘force themselves’, it is wise to check how far you can or want to go. We advise that you take these feelings seriously and that you withdraw if necessary in order to ensure that your coexistence remains as pleasant as possible.

### Practical guide “Sexuality”

It may be necessary to create opportunities for your family member to satisfy their needs.

What should you do about an increased need for intimacy?

- Provide closeness.
- Make physical contact: Embrace your family member or caress them. You can satisfy the need for intimacy by washing their back, arms or legs, applying creams or massaging them. If physical contact was not or is not common, then show more affection.

What should you do about masturbation among dementia patients?

- Allow them to masturbate, as long as they are not risking injury.
- Create space for the dementia patient to experience intimacy without disturbing others.
- Where necessary, provide them with suitable calendars, magazines, films, pharmacy products or other aids.

Should you allow sexuality as a caregiving partner?

- Only give the level of intimacy that you are comfortable with; move out of your shared bedroom if necessary!

What should you do about sexual disinhibition among dementia patients?

- Look for causes (consult a doctor, as it may be a side-effect of medication).
- Consider how the person’s needs can be satisfied (sexual surrogates, pornographic magazines etc.).
- If necessary, say clearly “No, I don’t want that!” (but do not be disparaging).
- Consult a doctor if the dementia patient is at risk of injuring themselves (the doctor can prescribe medication if appropriate).
- You and other family members may have to find protection!
- Seek professional help!

Learn more about the disease, e.g. in a counselling centre in the dementia service centres: [www.demenz-service-nrw.de](http://www.demenz-service-nrw.de)



## Addresses and literature

### Webpages

[www.alzheimerandyou.de](http://www.alzheimerandyou.de)  
[www.bundesgesundheitsministerium.de/pflege](http://www.bundesgesundheitsministerium.de/pflege)  
[www.demenz-service-nrw.de](http://www.demenz-service-nrw.de)  
[www.deutsche-alzheimer.de](http://www.deutsche-alzheimer.de)  
[www.integrative-validation.de](http://www.integrative-validation.de)  
[www.lpfa-nrw.de](http://www.lpfa-nrw.de) (Landesstelle Pflegende Angehörige NRW – State Office for Family Caregivers in NRW)  
[www.pflege-nottelefon.de](http://www.pflege-nottelefon.de)  
[www.pflegen-und-leben.de](http://www.pflegen-und-leben.de) (Online psychological counselling for family caregivers)  
[www.seelsorge.net](http://www.seelsorge.net)  
[www.wegweiser-demenz.de](http://www.wegweiser-demenz.de)

### Counselling centres

Landesstelle Pflegende Angehörige NRW – (State Office for Family Caregivers in NRW)  
Tel. 0800 2204400 (Mon and Wed 10 am – 12 pm)  
(Telephone counselling in all matters)

Crisis lines by the Christian churches in Germany:  
Protestant crisis line, tel. 0800 1110111  
Catholic crisis line, tel. 0800 1110222  
(Staffed 24/7)

### Literature and sources

Udo Baer, Gabi Schotte-Lange:  
Das Herz wird nicht dement – Rat für Pflegende und Angehörige  
Beltz 2013

Udo Baer:  
Wo geht's denn hier nach Königsberg? –  
Wie Kriegstraumata im Alter nachwirken und was dagegen hilft  
Affenkönig 2011

Prof. Sabine Engel:  
Alzheimer und Demenzen – Die Methode der einfühlsamen Kommunikation.  
Unterstützung und Anleitung für Angehörige  
Trias 2011

Vera Francz:  
Tag und Nacht verfügbar – Der Alltag pflegender Angehöriger  
Leykam 2006



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Hilfen zur Kommunikation bei Demenz, Demenz-Service Issue 2

Kuratorium Deutsche Altershilfe, Cologne 2012

Available as a printed brochure from [www.demenz-service-nrw.de](http://www.demenz-service-nrw.de)

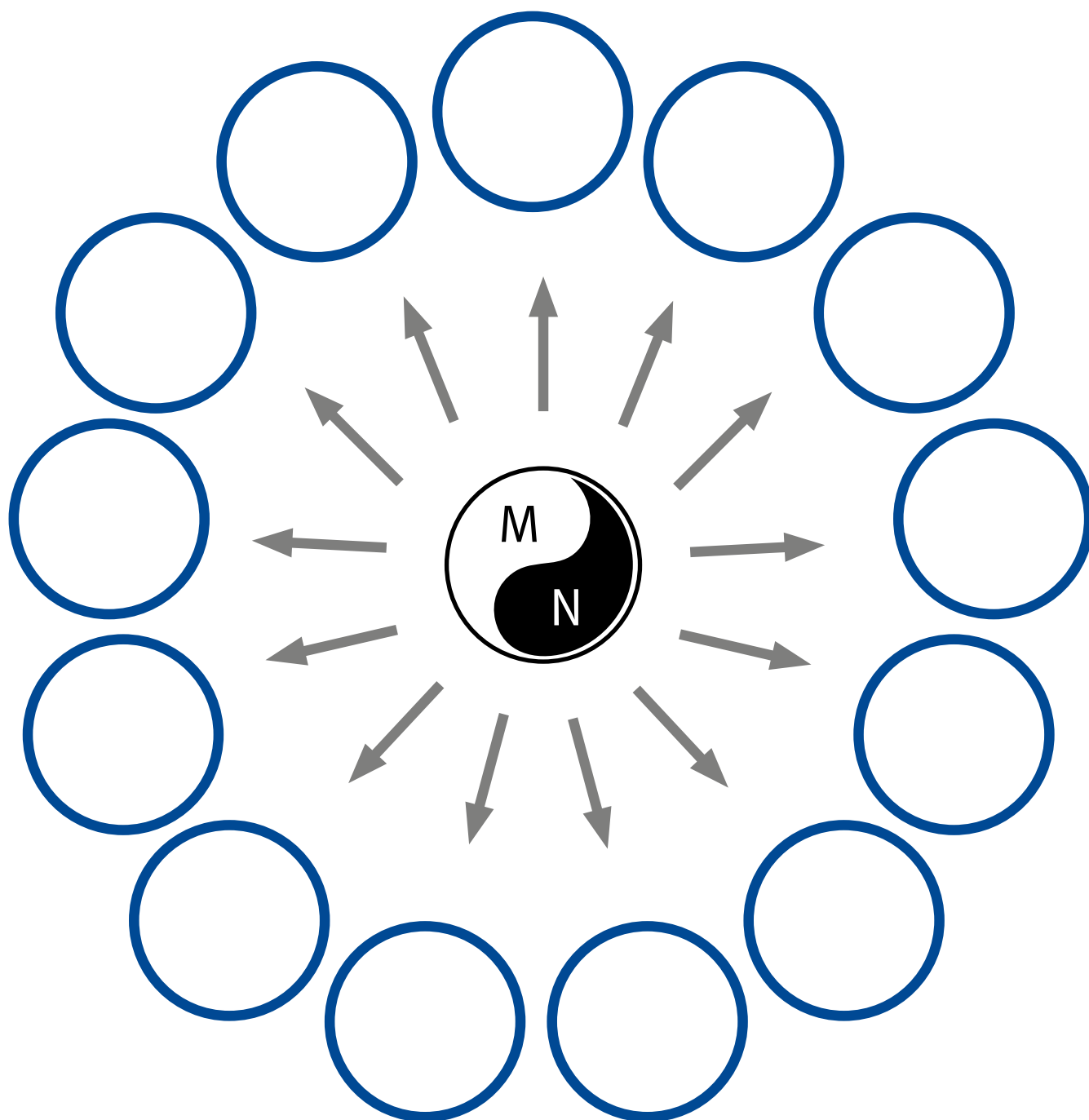
German National Association of Senior Citizens' Organisations (BAGSO) and

German Association of Psychotherapists (DPtV), pub.:

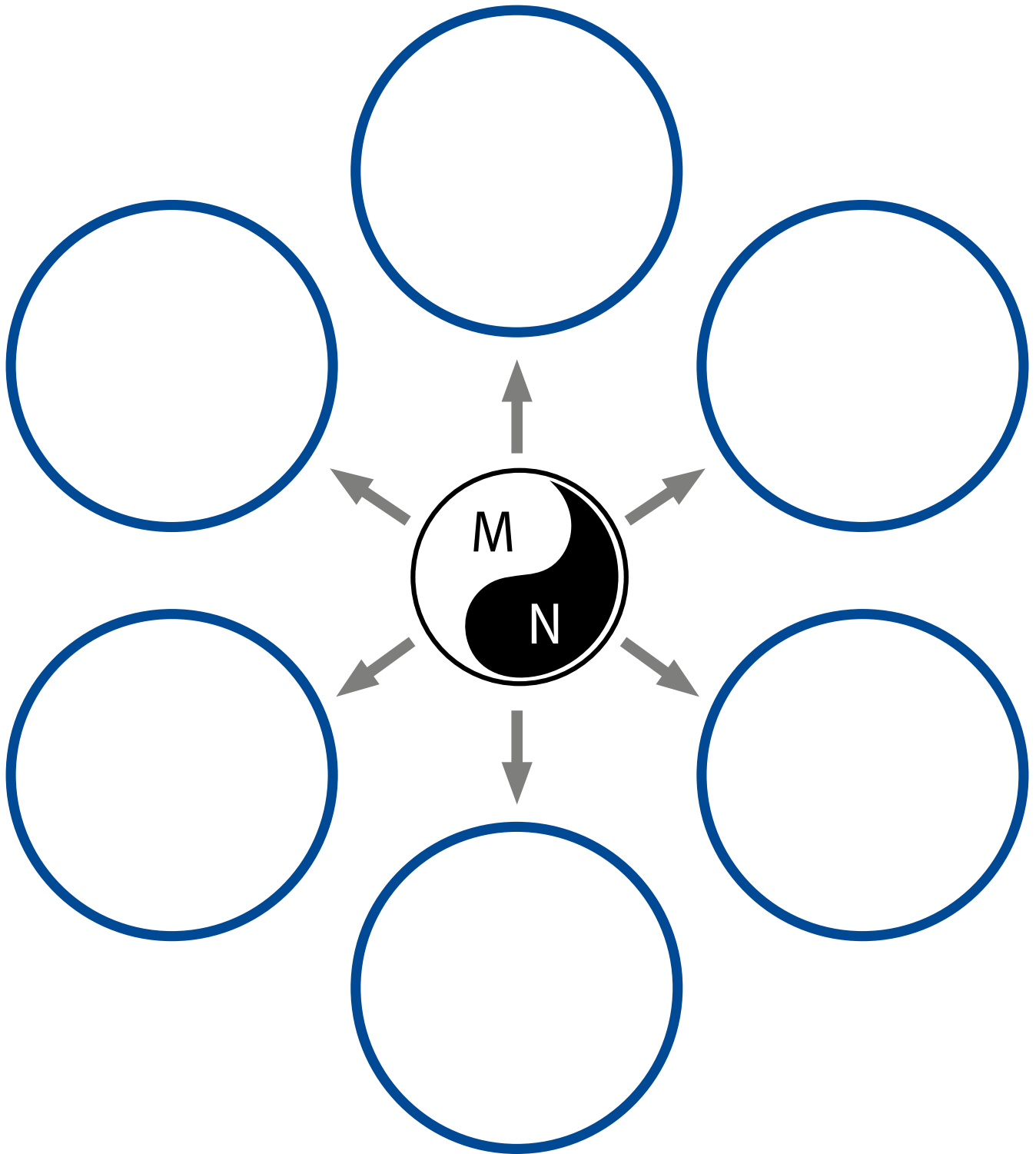
Entlastung für die Seele – Ein Ratgeber für pflegende Angehörige

Printable version available online by entering the title on the DPtV homepage











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