



WISSENSRAUM NO. 1

NAVIGATION ATLAS DEMENTIA

Forms, Causes and Holistic Care

“Look closely before accompanying.”

AKADEMIE DER WEISHEIT — WISSENSRÄUME

◆ 1. One Word, Many Realities

Dementia is an umbrella term, not a single disease.

A person receives the diagnosis “dementia”. From that moment on, a single word seems to explain everything: the forgetting, the disorientation, the change in behaviour, the loss of familiar abilities. Yet at first the word explains remarkably little.

In clinical terms, dementia is a syndrome: a combination of symptoms in which memory, thinking, language, orientation, judgement or behaviour are impaired to such an extent that everyday life can no longer be managed independently. What triggers this syndrome can be very different: protein deposits, circulatory disorders, the degeneration of particular brain regions, but also metabolic disorders or the effects of medication. According to current estimates, around 1.8 million people were living with dementia in Germany at the end of 2025; between 2.3 and 2.6 million are expected by 2050.

This Wissensraum is a navigation atlas. It does not lead through a lexicon of symptoms but through a question: Which dementia is present — and what does this knowledge change for the person, for their care and for the decisions ahead? It connects biology, clinical picture, behaviour, treatment and law, because in daily life these levels cannot be separated. Its guiding thought: the more precisely we distinguish, the less we have to reduce a person to a single word.

“A diagnosis gives the change a name. It does not yet tell us how this person experiences their world.”

◆ 2. The Map of Dementia Forms

Four forms shape the picture — and each calls for different support.

Over everything spreads the umbrella “dementia”. Beneath it lie diseases with their own cause, onset and course. Alzheimer’s disease is the most common form, accounting for roughly 60 to 70 per cent of cases; vascular dementia comes second. Dementia with Lewy bodies (around 5 per cent) and frontotemporal dementia (roughly 3 to 9 per cent) are rarer but change the picture fundamentally — and are the most often overlooked.

Alzheimer’s disease begins gradually. Short-term memory, word-finding and orientation suffer first; physical symptoms join only late. In the brain, beta-amyloid is deposited outside and tau protein inside the nerve cells, and nerve cells are lost progressively. Support here means structure,

familiar routines, memory aids and biographical work, in suitable cases supplemented by medication.

Vascular dementia often follows a stepwise course, frequently after strokes. Thinking is slowed, planning becomes difficult, and there is sudden confusion and neurological deficit. Its cause lies in disease of small blood vessels, in vascular occlusions and circulatory disturbances; the treatment of vascular risks therefore comes first, together with exercise, motor support and the prevention of further strokes.

Frontotemporal dementia, FTD for short, usually begins between the ages of 50 and 60 and shows itself first not in memory but in personality, behaviour or language: in disinhibition, tactlessness, loss of drive, ravenous appetite. It rests on the degeneration of the frontal and temporal lobes with deposits of tau or TDP-43 proteins; in roughly one in ten cases it is hereditary. Environmental design, de-escalation, protection from harm to self and others, speech therapy and counselling for relatives carry the support here.

Dementia with Lewy bodies is marked by strongly fluctuating attention and alertness, by visual hallucinations, by Parkinson-type symptoms such as rigidity, tremor and falls, and by sleep disorders in which dreams are acted out. Deposits of the protein alpha-synuclein, the “Lewy bodies”, are found in nerve cells of the cerebral cortex, among other places. Fall prevention, stimulus regulation and particular caution with antipsychotics matter here.

In addition there are mixed forms — most often Alzheimer’s disease combined with vascular damage, especially in advanced age —, Parkinson’s disease dementia, and secondary dementias caused by metabolic disorders, vitamin deficiency, alcohol, medication, infections or normal pressure hydrocephalus. Some of these are treatable or partly reversible. Parkinson’s disease dementia differs from dementia with Lewy bodies mainly in sequence: in it, movement disorders clearly precede the thinking disorders.

“Behind the one word lie different paths, and each needs different support.”

◆ 3. What Happens in the Brain

The cause in the brain determines how the disease shows itself.

Nerve cells work in networks, and each disease affects different regions. In Alzheimer’s disease, degeneration begins where new memories are stored — which is why memory is affected first. Its hallmarks include beta-amyloid between the cells and altered tau proteins within them. In vascular dementia, under-supplied areas are responsible, hence the often irregular, stepwise

courses. In FTD, the regions that control impulses, social behaviour and language suffer; personality changes while memory initially remains. In dementia with Lewy bodies, alpha-synuclein deposits disturb, among other things, attention and movement control.

And heredity? Most dementias are not hereditary in the narrow sense. In Alzheimer's disease, fewer than three per cent of cases are inherited in an autosomal-dominant manner; these forms usually begin before the age of 60. The gene variant ApoE-ε4 raises the risk but is never a cause on its own. Genetic testing therefore makes sense only with a well-founded suspicion and after counselling.

“Whoever understands where in the brain something is lost understands better what a person needs.”

◆ 4. When Symptoms Tell More Than Memory

What looks similar from the outside arises inside from very different processes.

Dementia is not recognised by forgetting alone. Language and language comprehension, planning and action control, impulse control and personality, attention and perception, spatial orientation and bodily control can all be affected. A person who can no longer plan an action needs different support from a person who no longer recognises the meaning of the action. Four typical, freely composed situations show how quickly neurologically caused changes are misread as unwillingness, malice or laziness.

A man asks for the fifth time when his wife will be home, and those around him say: He isn't listening. In Alzheimer's disease, however, the answer is not stored; for him the question is new every time, and the worry behind it is real. A woman recognises her family but reaches for food from the next table in a café, and people say: She does that on purpose. In FTD, impulse control and social judgement are lost early, while memory can remain intact for a long time.

Another man sees children on the sofa; at midday he is hardly responsive, in the evening clear, and it is suspected that he is putting on an act. Visual hallucinations and fluctuating alertness are, however, typical of dementia with Lewy bodies — and antipsychotics are particularly risky here. A resident, finally, is slowed down after several small strokes and can no longer put the steps of dressing in order, and it is said that she does not want to take part. In vascular dementia, thinking and planning are slowed; small steps, time and an unchanging routine help.

Each of these scenes asks the same question: What lies behind the behaviour?

“What looks like unwillingness is often an inability.”

◆ 5. Special Life Circumstances

Dementia is not a disease of old age alone.

When the disease begins before the age of 65, specialists speak of young-onset dementia. It is often Alzheimer’s disease, FTD or vascular dementia; hereditary factors play a greater role than in advanced age. Diagnosis often takes a long time because no one thinks of it — changes are first read as depression or exhaustion. Those affected are in the middle of working life, with children and financial commitments: reduced earning capacity, protection against dismissal, severe disability status, age-appropriate explanations for children, and services designed for older people that do not fit.

In people with Down syndrome, too, dementia shows itself earlier. The additional copy of chromosome 21 carries an additional copy of the gene for the amyloid precursor protein; the result is an overproduction of beta-amyloid and a greatly increased risk of Alzheimer’s disease. It can begin as early as the 40s or 50s and shows itself as a loss of acquired practical skills, a change of character or epileptic seizures. The danger lies in “diagnostic overshadowing”: changes are attributed to the disability instead of being investigated. A documented baseline, regular follow-up examinations and familiar people close by help.

Other biographies also change diagnosis and support: hearing impairment complicates tests and is mistaken for dementia; with migration experience, interpreters and culturally sensitive counselling are needed; people with LGBTIQ+ biographies need their chosen close persons recognised; those who live alone are particularly at risk of isolation and emergencies. Closeness and sexuality remain subjects that must not be taboo.

“Where the familiar picture does not fit, only a close look at this one biography helps.”

◆ 6. Diagnostics as a Search for Difference

A careful diagnosis seeks not only confirmation but also other explanations.

It begins with conversation: the person’s own history and — with consent — the history from relatives, since others often notice the change first. Physical and neurological examination, neuropsychological tests, laboratory tests and imaging (MRI or CT) follow, and where needed cerebrospinal fluid analysis or biomarker evidence for amyloid and tau. Blood and imaging markers increasingly allow earlier and more precise classification; they do not replace overall

medical assessment. The course over time is itself a diagnostic instrument. Memory clinics pool this expertise.

Above all, delirium must be distinguished — acute confusion and a medical emergency, often triggered by infections, dehydration or medication — as well as depression, side effects of drugs (especially substances with anticholinergic effects), hearing and vision problems, and vitamin and metabolic disorders. Delirium can also be superimposed on an existing dementia.

The conversation afterwards belongs to the diagnosis. People are entitled to comprehensible information (Section 630e of the German Civil Code) — and to decide for themselves how much they wish to know. Disclosure works best gently, with time and an offer to keep talking. Early clarification has a purpose beyond knowledge: as long as decision-making capacity holds, advance care and wishes can be arranged.

“Not every cognitive change is dementia.”

◆ 7. Treatment Begins with the Right Classification

There is no method for everyone — every measure must fit the disease, the stage, the biography and the situation.

In mild to moderate Alzheimer’s dementia, cholinesterase inhibitors (donepezil, galantamine, rivastigmine) are approved, and in moderate to severe Alzheimer’s dementia memantine. Rivastigmine is also approved for Parkinson’s disease dementia and, like other cholinesterase inhibitors, used in practice in dementia with Lewy bodies. They can stabilise abilities for a time but cannot halt the loss of nerve cells. In vascular dementia, treating the vascular risks comes first. In FTD, Alzheimer’s medication is not effective; behavioural symptoms are treated symptomatically, for example with antidepressants.

Newly added are lecanemab and donanemab, antibodies against beta-amyloid. They have been approved in the EU since 2025 for early Alzheimer’s disease — for people with mild cognitive impairment or mild dementia, with proven amyloid pathology and at most one copy of the gene variant ApoE-ε4. In the pivotal trials they slowed progression by roughly a fifth to a third; they are not a cure. They require close monitoring because of possible brain swelling and micro-haemorrhages and belong in the hands of experienced neurologists or psychiatrists with prompt access to MRI. The S3 guideline, updated in 2026, gives a weak recommendation (grade B) for treatment under these strict conditions, whereas the Federal Joint Committee (G-BA) found no proven additional benefit over previous standard therapy for either substance (lecanemab on 19

February, donanemab on 16 April 2026). Prescribing remains possible for people who meet the criteria; the antibodies come into consideration, however, only for a small proportion of those affected.

Antipsychotics are not standard remedies. In severe agitation or aggression, when other approaches are not enough, they can be considered briefly and under close monitoring — but they increase the risk of falls, strokes and mortality and must never serve merely to sedate. In dementia with Lewy bodies there is marked hypersensitivity; severe, sometimes life-threatening reactions are possible. The right diagnosis is therefore also a matter of safety.

Non-drug approaches are not an add-on but the core of treatment, and they differ by form. Rehabilitation, occupational therapy, physiotherapy and speech therapy are due to people with dementia just as to everyone else. In Alzheimer's disease the aim is independence and care of memory: biographical work, cognitive activation, occupational and music therapy, a structured day. In vascular dementia it is a matter of preventing and moving, of treating blood pressure, diabetes and blood lipids, of exercise for circulation, daily structure and psychosocial counselling. In FTD the task is to avoid conflict and secure protection, through behaviour management and de-escalation, environmental design and — in language variants — speech therapy. In dementia with Lewy bodies, safety and dealing with fluctuation come first: fall prevention and physiotherapy, safety in the face of hallucinations and stimulus regulation, for example through snoezelen.

“The best treatment is the one that fits this person.”

◆ 8. Understanding Behaviour Before Responding to It

Restlessness, withdrawal, calling out, resistance or apparent refusal are messages.

They say: something is not right here — even when words are missing. Before a reaction follows, eight questions help, laid like an inner circle around the person. Is the person in pain? Is it too loud, too bright, too confusing? Do they feel threatened or alone? Did they understand the request at all, and is the task not too complex for them? Is there a delirium or a physical illness — an infection, urinary retention, constipation, thirst, hunger? Is a personal boundary being crossed, through shame or an intrusion on privacy? And finally: is the behaviour an expression of the affected brain region, for example the frontal lobes?

This joins neurological knowledge with person-centred support, as the national expert standard on relationship-building in the care of people with dementia also demands: short clear sentences, calm, eye contact, the familiar instead of correction.

“The aim is not sedation but understanding.”

◆ 9. The Body Keeps Speaking

When language becomes uncertain, the person’s message does not end — it changes form.

People with dementia often can no longer name pain, and it is therefore underestimated. It shows itself as restlessness, resistance, calling out or moaning, grimacing, guarding postures, altered breathing or muscle tension, withdrawal or refusal of food. Observation scales such as BESD, PAINAD or BISAD help to record these signs systematically. Drug-based pain therapy can be guided by the WHO analgesic ladder, from non-opioids to opioids; it is weighed individually by the physician, carefully dosed and regularly reviewed.

Other needs of the body are easily overlooked: oral health — toothache or ill-fitting dentures lead to refusal to eat, swallowing problems and pneumonia —, urinary tract infections and constipation, nutrition, fluids and movement. A regular medication review belongs here, especially for substances with anticholinergic effects. A hospital stay carries a risk of delirium and loss of orientation for people with dementia; familiar companions and a sheet with the most important habits help.

“Where words end, the body keeps speaking.”

◆ 10. Self-Determination, Protection and Law

A diagnosis of dementia does not automatically mean the loss of self-determination.

In law, precise distinctions matter. The diagnosis is a medical finding. Capacity to consent means whether a person understands the significance and consequences of a specific decision and can form their will — it is decision- and situation-specific and can fluctuate. Legal capacity to contract concerns the ability to conclude contracts validly. The natural will remains relevant even when insight is lacking. Advance care, guardianship and protection can be arranged along the course of the disease in three stages, without the stage alone deciding.

In the early stage the task is to make provisions while decision-making capacity holds: with a power of attorney for care, an advance directive (regulated in Section 1827 of the Civil Code since the 2023 guardianship reform), a guardianship directive and arrangements for finances and digital access. Powers for particularly high-risk treatments and for measures depriving liberty must be granted expressly and in writing in a power of attorney.

If a person's own capacity to decide and act no longer suffices for certain matters and there is no adequate power of attorney, legal guardianship (Sections 1814 ff. Civil Code) may become necessary — but only where necessary and only for the areas of responsibility set by the court. It is meant to support first and represent only then, and it follows the wishes and natural will of the person under guardianship. For spouses and registered partners, Section 1358 of the Civil Code provides in an acute illness situation for temporary representation in health matters, for six months at most; it does not replace a power of attorney.

In situations of danger, finally, deprivation of liberty is always the last resort. Restraints, locking doors, bed rails depending on the case, or medication to sedate are serious interferences with a fundamental right (Article 2(2) of the Basic Law). For people under guardianship, when applied regularly or over a longer period they require the decision of the authorised representative and the approval of the guardianship court (Section 1831 Civil Code); medical coercive measures are subject to the strict requirements of Section 1832. Alternatives always take precedence. Not the diagnosis but the concrete danger decides; an increased risk of falling alone does not justify restraint.

Fitness to drive and the right to vote also call for the individual view. Whether someone may still drive must be clarified medically in each case. In FTD (disregard of rules, impulsivity) and dementia with Lewy bodies (hallucinations, fluctuations), fitness to drive can be lost very early, before pronounced memory problems. An early conversation and alternatives such as transport services help; where there is considerable danger to others, medical confidentiality may in individual cases give way. The right to vote remains: since 2019 there has been no blanket exclusion from voting for people under legal guardianship in all affairs, and support from an assistant is permissible as long as it does not influence.

“Not the diagnosis decides, but the person and the concrete situation.”

◆ 11. When Eating and Drinking Become Ethical Questions

Does a medically possible measure still serve this person's life — or does it mainly prolong a condition they might not have wanted for themselves?

As dementia advances, swallowing, hunger and thirst change. Refused food is usually not “not wanting” but “not being able”: food is no longer recognised, the situation is not understood, handling cutlery fails. First the causes must be sought — mouth, teeth, pain, medication, surroundings — and the meal made a calm, attentive situation. Where a swallowing disorder exists, swallowing assessment and speech therapy belong to it.

If the question of a feeding tube (PEG) remains, it is not a routine decision. It requires a medical indication and the consent of the person or, if they can no longer consent, their established will — from an advance directive, treatment wishes or presumed will. For severe dementia there is no evidence that a tube prolongs survival or prevents pneumonia; in FTD it is often not tolerated. Where physicians and representatives disagree, the guardianship court is to be involved (Section 1829 Civil Code); ethics consultation and case discussion help with weighing. In the late phase, relief of pain and breathlessness and human attention move to the centre.

The ethical principles and case discussion are treated in Wissensraum No. 2 — The Ethical Compass in Palliative Care; legal foundations, care pathways and end-of-life decisions are arranged in Wissensraum No. 4 — Palliative Care 2026: The Architectural Foundation; the questions of illness, suffering, death and spirituality are unfolded in Wissensraum No. 19.

“A feeding tube is not a routine; it is a question about this person's will.”

◆ 12. A Whole System Falls Ill

Relatives are the most important pillar of care — and need care themselves.

Dementia changes roles: the partner becomes the carer, the son the decision-maker, children become those in the know who need an age-appropriate explanation. Guilt, overload and isolation are signs of strain, not of failure. Questions of work, pension and income follow. Those who accept help do not care worse but better. The fine border between caring and carrying is considered in Wissensraum No. 23 — Care in the Light of Ayurveda.

Long-term care insurance provides benefits that must be actively applied for. Since 2017, the assessment has weighed cognitive and psychological impairments equally with physical ones. The amounts change; for 2026, among others, the following apply: a care allowance for home care of

€347 (care grade 2), €599 (grade 3), €800 (grade 4) and €990 (grade 5) per month, a relief amount of up to €131 per month in all care grades, and a combined annual amount for respite and short-term care of up to €3,539 (since 1 July 2025). Day and night care, the supplement of €224 per month for outpatient shared-housing groups and grants for adapting the home are added.

The way there is shown by care counselling (Section 7a, Book XI of the Social Code), care courses, counselling centres and self-help groups; current amounts are given by the care insurance fund and the care support centre. How fragile the net can be when the main carer suddenly drops out is shown by the case study in Wissensraum No. 5 — System Breakdown at 8:30 PM.

“Care endures only for those who are themselves carried.”

◆ 13. Prevention and Research

Prevention is possible to a limited extent; a cure is not yet.

Modifiable risk factors include hearing loss, vision loss, high blood pressure, diabetes, depression, smoking, physical inactivity, social isolation and air pollution. International analyses estimate that a considerable share of cases — up to 45 per cent — could be delayed or avoided by prevention. That is a finding about populations, not a promise for the individual: a risk factor is not fate, and prevention guarantees nothing. Those seeking help also often meet half-truths and promises of miracle cures on the internet; for most dietary supplements and “miracle remedies” there is no proof of effectiveness.

Research is moving quickly: blood biomarkers, inflammatory processes, the gut–brain axis, environmental factors, artificial intelligence in diagnostics. Much of this is not yet conclusively proven and not a standard of care. Those who take part in clinical trials do so after careful information and of their own free will.

“Prevention is a finding about populations, not a promise for the individual.”

◆ 14. Conclusion — From Knowledge to Attitude

The best map only helps those who are ready to meet the person.

Dementia demands knowledge, because ignorance leads to misinterpretation. It demands observation, because needs do not always show themselves in words. It demands legal clarity,

because protection and self-determination can come into tension. And it demands an attitude that still perceives the person where their familiar abilities fade.

This attitude fits in three sentences. I ask before I interpret — behaviour is a message. I look for the reason before I react — pain, fear, overload and delirium come first. I see the person, not the diagnosis — in language too: we speak of people with dementia.

A navigation atlas cannot fix the path for all people. It can help us look more closely: at the biological cause, at visible behaviour, at the life story and at that reality in which the individual is still present.

“Accompanying dementia means learning to distinguish — and not losing the person in the process.”

∞ Further Exploration

Those who wish to pursue the questions touched on here will find adjacent explorations in the WISSENSRÄUME series:

- Wissensraum No. 2 — The Ethical Compass in Palliative Care
- Wissensraum No. 4 — Palliative Care 2026: The Architectural Foundation
- Wissensraum No. 5 — System Breakdown at 8:30 PM
- Wissensraum No. 19 — Palliative Care – Illness, Suffering, Death and Spirituality
- Wissensraum No. 23 — Care in the Light of Ayurveda

◇ Sources & Lines of Thought

This Wissensraum does not make a scientific argument. The following works show what its professional and scientific statements connect to — above all those of chapters 2, 3, 6, 7, 10, 11, 12 and 13.

- Deutsche Gesellschaft für Psychiatrie und Psychotherapie, Psychosomatik und Nervenheilkunde (DGPPN), Deutsche Gesellschaft für Neurologie (DGN): S3 Guideline Dementia (S3-Leitlinie Demenzen). 2026 version, AWMF register no. 038-013. Diagnosis, treatment and care, including the classification of antibody therapies.
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- G. Livingston et al.: Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission. *The Lancet* 404 (2024), 572–628. On modifiable risk factors.
- German Civil Code (Bürgerliches Gesetzbuch, BGB), Sections 630e, 1358, 1814 ff., 1827, 1829, 1831 and 1832 as amended by the reform of guardianship law (in force since 1 January 2023); Social Code Book XI, Section 7a.
- Bundesministerium für Gesundheit (Federal Ministry of Health): Overview of long-term care insurance benefit amounts 2026 (Übersicht über die Leistungsbeträge der Pflegeversicherung 2026).

→ Deutsche Alzheimer Gesellschaft: Information sheet 1 – The prevalence of dementia (Die Häufigkeit von Demenzerkrankungen). Berlin, current version.

○ WISSENSRÄUME — Appreciation

The WISSENSRÄUME series is a labour of love — free of charge, but not to be taken for granted. If these impulses have meant something to you and you would like to give something back, I welcome a voluntary donation: [PayPal.me/VossKati](https://paypal.me/VossKati)

Thank you for your appreciation. It helps such content continue to come into being — quietly, lovingly, and in the service of wholeness.

△ WISSENSRÄUME — Notes

The WISSENSRÄUME serve professional orientation, deepening and personal engagement with themes from health, nursing, palliative care, spiritual care, psychology and philosophy. They do not replace individual medical, therapeutic, nursing or legal advice — for acute or serious concerns, please turn to appropriately qualified professionals.

Sudden confusion or acute danger is a matter for the emergency number 112; outside surgery hours, the on-call medical service can be reached in Germany at 116 117. The legal provisions and amounts given reflect the position in October 2026 and may change.