

WISSENSRÄUME · KNOWLEDGE SPACE NO. 1

Navigation Atlas Dementia: Forms, Causes and Holistic Care

A clinical compass from biological diagnosis to
legal safeguarding.

AKADEMIE DER WEISHEIT



Dementia is an umbrella term – a syndrome with different causes

Alzheimer's disease

About 60–70 % of cases. Insidious onset.

Cause: deposits of β -amyloid plaques (outside the nerve cells) and tau protein (inside the nerve cells), along with impaired brain glucose metabolism.

Vascular dementia

Stepwise course, often after strokes.

Cause: disease of the small blood vessels, vascular occlusions (infarcts, lacunes) and reduced blood flow in the brain.

Frontotemporal dementia (FTD)

Personality in focus.

Cause: degeneration of the frontal and temporal lobes (deposits of tau or TDP-43 protein). About 10 % of cases are genetic.

Lewy body dementia

Fluctuating symptoms combined with Parkinson-like signs.

Cause: abnormal clumps of the protein alpha-synuclein (Lewy bodies) inside the nerve cells of the cerebral cortex.

Early signs at a glance

	Alzheimer's	FTD	Lewy body	Vascular
Primary early symptoms	Short-term memory loss, word-finding difficulties, disorientation.	Personality change, tactlessness, disinhibition, apathy (memory initially preserved).	Strongly fluctuating attention , visual hallucinations.	Slowed thinking, difficulty planning and organizing, sudden confusion.
Motor / physical signs	Relevant only in late stages.	Parkinson-like movement disorders possible, food cravings and overeating.	Parkinsonism (muscle rigidity, tremor, frequent falls), REM sleep behavior disorder.	Neurological deficits (signs of stroke), vision problems.

Two paths to an earlier onset

The genetic bridge (Down syndrome)

Trisomy 21 means an extra copy of the amyloid precursor protein gene, so the body produces more β -amyloid. Alzheimer pathology develops in almost every person with Down syndrome.

Clinical picture: an earlier onset, often from the 40s or 50s. Symptoms include a loss of previously acquired practical skills, personality change and epileptic seizures.

Younger age (young-onset dementia, YOD)

When dementia begins before the age of 65, inheritance plays a considerably larger role (autosomal dominant forms, though these remain rare).

It leads to an extremely rapid, often unprepared change of roles in families and calls for early, specific legal representation, in particular regarding **parental custody** (§§ 1673–1678 BGB) where minor children are affected.

Drug treatment – three levels of care

Standard antimentia drugs (approved)

Cholinesterase inhibitors (donepezil, rivastigmine, galantamine) and the NMDA antagonist memantine. Used in Alzheimer's disease; in Lewy body dementia, cholinesterase inhibitors (rivastigmine) are also recommended.

Symptomatic treatment (off-label)

Antidepressants (SSRIs) may be used in **FTD** to ease behavioral symptoms, because the classic Alzheimer's drugs are ineffective there and may make symptoms worse.



Extreme caution

Antipsychotics (neuroleptics): use only as a last resort, at the lowest dose and for a limited time, and **never merely to sedate**. **Warning: extreme sensitivity in Lewy body dementia, with potentially fatal reactions.**

In vascular dementia the focus is on medical control of vascular risk factors (blood pressure, diabetes, cholesterol). The newer anti-amyloid antibodies (lecanemab, donanemab) may be prescribed only in a very early stage under strict criteria; in 2026 the G-BA found no proven additional benefit.

Recognizing pain without words

Recognizing without words

Because affected people can often no longer express pain, non-verbal signals must be observed closely: restlessness, defensive behavior, moaning, grimacing, altered breathing.

Step 1

Non-opioid analgesics, such as paracetamol. NSAIDs such as ibuprofen only with caution, because of stomach, kidney and cardiovascular risks in older people.

Steps 2 & 3

Weak to strong opioids. Used only after careful medical assessment and under close monitoring.

Keeping comorbidities in view

Oral hygiene and dental care (preventing swallowing disorders and pneumonia); physical therapy to prevent painful stiffening.

Toolkits by form of dementia (1)

Alzheimer's toolkit

- Cognitive stimulation and biography work.
- Occupational therapy and music therapy.
- Structured daily routine and basal stimulation.

Focus: preserving independence and consciously nurturing memories.

Vascular toolkit

- Treating the underlying vascular risks (blood pressure, diabetes, cholesterol).
- Physical activity to actively support cerebral blood flow.
- Structuring everyday life and psychosocial counseling.

Focus: preventing further strokes and supporting movement.

Toolkits by form of dementia (2)

FTD toolkit

- Behavior management and proactive de-escalation.
- Milieu therapy: avoiding threatening situations and consistently adapting the home environment.
- Speech and language therapy (especially for the language variants of FTD).

Focus: avoiding conflict and protecting against harm to self or others.

Lewy body toolkit

- Fall prevention and physiotherapy (because of pronounced Parkinsonism).
- Safety measures and a calm, reassuring approach to visual hallucinations.
- Snoezelen (multisensory relaxation) for sensory calming.

Focus: physical safety and managing marked day-to-day fluctuations.

Decline of legal capacity – three moments

Early stage – still able to act

Drawing up the power of attorney and advance directive, and arranging finances. Legal capacity should be confirmed by a physician at this point.

Middle stage – loss of legal capacity

The guardianship law takes effect (§§ 1814 ff. BGB). Decisions are now made according to the person's **natural will**, guided by their previously expressed wishes.

Situations of danger

In FTD often early on: measures that restrict liberty (restraints, bed rails) or placement under the state mental health acts (PsychKG) only as an absolute last resort, and always with judicial approval (§§ 1831, 1832 BGB).

Decline of legal capacity

Driving fitness and the right to vote

Driving fitness (driving a car)

- Must be assessed medically on an individual basis (driving fitness check).
- **Caution:** in FTD (aggression, disregard for rules) and Lewy body dementia (hallucinations, fluctuations), driving often has to be stopped very early.
- **Legal note:** medical confidentiality may be set aside in cases of acute danger to others (for example, a patient without insight who keeps driving).

The right to vote

- In principle it always remains.
- **Fact:** since 2019, people under full guardianship in Germany are no longer excluded from voting.
- **Support:** there is a legal entitlement to assistance from helpers when voting.

Feeding tubes and care in the final phase

Core decision: feeding tubes (nasogastric tube, PEG)

Tube feeding requires informed consent or must be derived from the presumed will of the person (for example, from an advance directive).

Clinical nuance (FTD)

In frontotemporal dementia a tube is often not tolerated because of the illness: foreign objects on the body are pulled out reflexively. This has to be weighed early and in line with the person's wishes.

Palliative care

In the late phase the focus is on pain management and relief of breathlessness rather than prolonging life at any cost. Ethics case conferences (ethics committees) are advisable when there is no clear advance directive.

Support for those who care

Social and psychological strain

Coping with drastic changes in personality (especially in FTD), social isolation and feelings of guilt. Counseling for relatives is urgently needed (for example, through Alzheimer societies).

Impact on work

Protection against dismissal, sick leave, early retirement. Massive financial loss due to inability to work, especially critical in young-onset dementia (YOD).

Support structures

Apply proactively for benefits: long-term care insurance (SGB XI), residential group supplement (§ 38a SGB XI), help with care (SGB XII), and recognition of severe disability.

Biology, behavior, environment

Dementia is not a single disease. The precise biological cause shapes the behavioral symptoms. Because no drug can cure dementia, the tailored legal, social and environmental architecture becomes the actual “treatment.”

1. Diagnosis dictates safety

Antipsychotics are a last resort even in Alzheimer’s disease and can be fatal in Lewy body dementia. Precision saves lives.

2. Law before crisis

Subtypes such as FTD call for early driving cessation and powers of attorney well before classic memory is lost.

3. Environment as therapy

Milieu therapy and legal planning ahead protect equally the dignity of the person and the lives of their relatives.