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'Don't kill them' - Dementia, dying, wanting to die

>> In 2020, the ban on assisted suicide in Germany was declared unconstitutional. The Federal Constitutional Court argued at the time that the right to life also includes the freedom to take one's own life and to resort to voluntary help from third parties. However, it failed to draw up a clear legal framework for doctors at the same time - with the result that assisted suicide has been in a legal grey area since that day (1).

There is no discussion about active euthanasia, which is still prohibited in Germany. However, passive euthanasia - the renunciation, cancellation or reduction of initiated life-prolonging measures - indirect euthanasia - in which medication is used that results in a reduced or suspended level of consciousness - and assisted suicide - in which a lethal agent is procured or provided but, in contrast to active euthanasia, must be taken by the patient themselves - are not prohibited in principle.

At the beginning of July 2023, the attempt to agree on a new legal regulation on assisted suicide in the Bundestag failed. Of the two draft laws that were drawn up by cross-party parliamentary groups, neither received a majority. The first initiative came from MPs led by SPD politician Lars Castellucci. The draft envisaged making assisted suicide a criminal offence in principle, but allowing it under certain conditions. The person wishing to make use of assisted suicide would have to be of legal age, be examined at least twice by a psychiatrist and undergo a counselling session.

The groups led by Green Party politician Renate Künast and FDP politician Katrin Helling-Plahr, on the other hand, had agreed on the basic position that the right to self-determined death should be enshrined in law without criminal penalties. Every person should be allowed to help another person who wishes to end their life of their own free will to commit suicide at their request and accompany them until death occurs. These parliamentarians reject a psychiatric expert opinion, as contained in the Castellucci group's draft. Instead, those willing to die should be given access to lethal medication if they have received counselling beforehand.

The fact that the Bundestag was unable to agree on either option during emotional debates is a reflection of the social discourse on this topic, which also plays a role time and again in the day-to-day care of people with dementia. This is not (only) about the possibility of assisted suicide, but fundamentally about the question of how to deal with the wish to be allowed to die with progressive or advanced dementia.

As part of my counselling work, I often come across people who express the assumption that they will certainly no longer want to live if they develop dementia. It is often relatives who ask themselves whether the person with dementia they are caring for would want to continue living if they could decide for themselves. And sometimes people who already have dementia also express the wish to die - not immediately, but at a later date. They also fear that at some point they will no longer be able to make a self-determined decision in favour of or against life: What will happen if the care crisis becomes ever greater and care becomes less and less affordable? Will there perhaps be family or societal pressure for people with dementia in particular to choose the path of suicide?

Everyone should have the opportunity to decide whether they want to live or not. However, the prerequisite for this must be that the decision has been made clearly and unambiguously of one's own free will and with a clear mind over a long period of time and is not based on economic reasons or the fear of being a burden to other people.

People with dementia can still make their own decisions at all stages of the disease - but with varying degrees of autonomy. This is well expressed in the position paper of the German Alzheimer's Society on the subject of assisted suicide: In the first few years after diagnosis, it is usually possible for those affected to assess the consequences of decisions and - based on values and experience - to form a stable opinion on this. In this phase, they are therefore also able to make a serious suicide decision (2). However, as the dementia progresses, it can no longer be assumed that a formulated wish for suicide unequivocally corresponds to the person's current will. For this reason, assisted suicide is also no longer possible in Switzerland in the case of advanced dementia (3). However, it can be stipulated there that life-prolonging medical treatment and artificial nutrition and hydration should be avoided in the case of advanced dementia. In Germany, too, statements of this kind in living wills are initially legally binding (4).

In the Netherlands, active euthanasia is also permitted for people with severe dementia. A written living will is recognised even if the patient is no longer responsive, according to a ruling by the High Council in The Hague. This judgement was prompted by a highly controversial case in which a doctor had performed active euthanasia on a woman suffering from severe dementia in a nursing home in 2016 and was ultimately acquitted of the charge of murder by the High Council. The 74-year-old woman had stated in writing that she wanted to die in the event of unbearable suffering due to dementia. However, at the time of the euthanasia, there were probably signs that she wanted to live - but she was no longer responsive herself (5).

In the Netherlands, a living will therefore takes precedence over the supposedly current natural will of the person concerned. And it is precisely at this point that the ultimately existential conflict becomes apparent: How should a wish to 'not want to live' be dealt with, which was already made at an earlier point in time in a healthy state or at the onset of dementia and relates to the future, a potentially altered state of illness? Can a person with dementia decide to end their life at a time when they can clearly form and express their will, if they are no longer able to make this decision in the case of advanced dementia? What happens to people who, at a later stage of de-

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mentia, make it clear in their own way that they want to live - even if they have decided otherwise at another time?

The Bonn psychiatrist Wolfgang Maier emphasises that living wills anticipate situations that have not yet been experienced by the individual and that the imagined experience can therefore differ greatly from the actual experience. And so, even in the run-up to or in the first years of dementia, it is generally impossible to imagine how life will feel subjectively in a later state of dementia - and whether and in what form it will be perceived as worth living (6).

Time and again, I experience people with dementia who, especially in the middle phase of the disease - i.e. in the period between often gruelling reflection and grief on the one hand and severe need for care on the other - feel recognisable joy in their lives and also express this - albeit often in a different way than was the case in other phases of life. As Maier also points out, it can happen that people with dementia do not (or no longer) perceive their own situation as so stressful (no longer) experience their own situation as stressful and undignified as they once imagined, but have ruled out life-sustaining medical measures in the event of dementia on the basis of prior assumptions in their living will. Anyone can change their decision in favour of or against life - at any time and in any state of illness. Experience shows that a number of people at a younger age assume that life-sustaining measures should be ruled out in the event of illness - and then wish for them in the specific case and with increasing age.

Although these statements and conclusions initially relate to passive euthanasia and living wills, they can also be applied to assisted suicide: the wish for this must have been expressed as long as the person with dementia is cognitively capable of doing so. And it can also be realised at an earlier stage of the disease, provided that all legal and ethical requirements and guidelines are met. However, as the dementia progresses and the person loses their decision-making capacity, it is no longer possible to clearly judge whether they feel that their life with the disease is no longer worth living. Assisted suicide is further complicated by the fact that a lethal medication can only be made available, but must be actively taken by the person concerned. But how can you be sure that a person with advanced dementia is really aware of the lethality of this medication and its irreversible consequences? This clarity cannot be achieved, and therefore assisted suicide in advanced dementia cannot be realised under any circumstances.

Ultimately, constant observation is required: Is what the person expressed as a wish at another time transferable to the current situation? Specifically in relation to people with dementia: Does the person with dementia show a zest for life, even if they are no longer cognitively able to express this to others in an understandable way and, if necessary, revise their wish to end their life? An example of this is the well-known 'Don't kill yourself' by the late Walter Jens (7). It is also possible that a person with dementia does not want to open their mouth when food is served and does so over a longer period of time - which can be interpreted as a sign of a lack of desire to live, especially if a corresponding living will is in place. These observations are also appropriate for people who do not have a living will and have never stated that they no longer want to live in the event of (advanced) dementia - because their perception of quality of life, their attitude to 'wanting to live' can also change over the course of the illness.

It is therefore important to support people with dementia with empathy and to always keep an eye on whether they appear to feel that their life is worth living. Here, medicine, law and ethics should always work together so that it can be ruled out in every case that reasons other than the individual motives of those affected play a role. If the person with dementia expresses over a longer period of time that they no longer want to live using the available means of communication, a known biography and recognisable suffering, there are possibilities for passive, indirect euthanasia. But even if there is the slightest doubt, we believe that the path of life should always be chosen and the person should be given palliative care and, if necessary, pain relief. Quality of life until the last day - that must be our goal, whenever that last day may be. <<

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