

**Opinion No 89 of 10. November 2025
relating to euthanasia on the basis of an
advance directive in conscious persons
whose capacity to decide for themselves
and express their will is irreversibly
impaired**

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Preliminary Warning:

The Committee's opinions are drafted in Dutch and French. Please consider these two language versions as official, even if translations in other languages are available.

Request for an opinion

Following public debate, the Belgian Advisory Committee on Bioethics decided, at its plenary session on 18 November 2019, to issue an opinion on its own initiative (self-referral) concerning the possible ethical relevance of extending the scope of the advance euthanasia directive to persons suffering from a pathology which suddenly or progressively impairs their capacity to make decisions by and for themselves, but not leading to a situation of irreversible unconsciousness, the only situation which, under the current legal framework, allows an advance euthanasia directive to be considered. Hearings were held, involving individuals affected by such a situation (patients or family), representatives of patient associations or palliative care federations, and healthcare experts. Documents from scientific research, the media and guidelines were consulted. The work of the Committee had to be suspended following urgent instructions relating to the COVID-19 pandemic and resumed at the end of 2023.

In parallel with the work initiated on its own initiative, the Committee received in October 2024 a request for an opinion from the Commission for Health and Equal Opportunities of the Chamber¹. The Chair of the Committee indicated in a letter dated 13 November 2024 that the referral was admissible. It is the result of all the hearings, work and reflections initiated on this subject that forms the substance of this opinion.

¹ Request for an opinion dated 25 October 2024 from the Commission for Health and Equal Opportunities of the Chamber of Representatives concerning the bill amending the law of 28 May 2022 on euthanasia with a view to extending the advance declaration of euthanasia to persons who have become incapable of expressing their will. (DOC 56.183/001).

1. Introduction: ethical issues and scope of the opinion

The legal framework currently provides for two types of request for euthanasia:

- A "current" request for euthanasia, made by a person who is capable of deciding for him or herself, with a view to the euthanasia being performed in the days or months that follow. An affirmative response to such a request implies, among other things, that the request must be "voluntary, considered and repeated"; that the person making the request must suffer from a serious and incurable condition and be in a hopeless medical situation; and that the person must "report constant and unbearable [...] suffering that cannot be alleviated and that results from a serious and incurable condition"².
- An advance directive concerning a future situation, which can only be taken into account as a basis for a decision to implement euthanasia if the patient "is suffering from a [...] serious and incurable condition, and is irreversibly unconscious according to the current state of science"³ (art. 4, § 2):

Neither of these two possibilities allows euthanasia to be performed on individuals who, while not unconscious, are judged to have become incapable of making decisions by and for themselves as a result of a pathology that impairs this capacity (see below the medical situations that can lead to such a decline in this capacity): the capacity to decide is deemed too impaired for euthanasia to be considered as part of a "current request", and the condition of being irreversibly unconscious or in a coma, which allow for euthanasia to be implemented on the basis of an advance directive, is not met. Representatives of patients and their families point out that patients suffering, for example, from a neurodegenerative disease sometimes resort to early euthanasia, while they are still fully capable of deciding for themselves, in order to satisfy the conditions of the "current request for euthanasia" given the unpredictability of how their cognitive capacities will evolve and the fact that the advance directive does not apply to what they will subsequently experience. They deprive themselves - and their family - of months or years of life of a quality that is still acceptable in their own view.

The following individuals are potentially affected by such a situation, in the event that an advance directive is drafted prior to an irreversible impairment of the capacity to decide for themselves:

² Law of 28 May 2002 on euthanasia, see below for the Belgian legal context (Art. 3).

³ Ibid. (Art 4 §2),

- individuals with neurodegenerative diseases (Alzheimer's, Huntington's, Parkinson's, etc.);
- individuals with cerebral palsy (e.g. as a result of an accident or stroke).

Although neurodegenerative diseases, and in particular the symptom of dementia that may be associated with them, are often cited as exemplary, it is indeed all situations of pathological deterioration, whether progressive or sudden, of the capacity to decide for oneself regarding a "current request" for euthanasia that are considered in this opinion. Situations where individuals are considered incapable of making decisions for themselves due to a congenital condition are excluded from this opinion: the Advisory Committee on Bioethics would like to recall that euthanasia can only be considered within the Belgian legal and ethical framework as responding to a request from the person in question and on the basis of certain strict conditions. In the case of neurodegenerative diseases, the progression of the disease can lead to gradual impairment of the ability to make decisions in general, including decisions regarding the patient's conception of how they want their life to end. This loss of ability does not occur suddenly, it is a slow process, during which the cognitive and psychological ability to make certain decisions gradually diminishes - although the speed and stages of this evolution vary from person to person, and it is difficult to pinpoint exactly when they are no longer able to make decisions for themselves in this respect.

As the disorder progresses, the question of euthanasia, with reference to an advance directive, may resurface, either on the patient's own initiative, or at the request of their family or family, or if carers who are aware of this advance directive confirm that the person is subject to severe suffering.

In the present opinion, the Committee intends to investigate the ethical issues linked to:

- the difficulty, if not the impossibility, of obtaining confirmation of the patient's wish to receive euthanasia in a context of pathological impairment of his or her capacity to decide for himself or herself on his or her initial directive of euthanasia;
- changes in habits and tastes, and even - potentially - changes in outlook and values, which can sometimes accompany cognitive changes that affect the ability to make decisions for oneself.

Since the patient is still conscious, he or she may react to stimuli or express wishes and preferences verbally or non-verbally, which can make it difficult for those around and caring for him or her to express what used to matter to the person (the *then-self*) and what appears to matter to him or her now (the *now-self*). During the course of the investigation for the present self-referral, it became clear to the Committee that a fundamental ethical guideline had to be respected, for the safety of the person in question, as well as for the safety of carers and family, and for society as a whole: in a context where it is no longer possible to obtain confirmation of the person's wishes (due to the pathology in question and even though the

person in question is still conscious), it is advisable to have an explicit statement of the patient's wishes, in the form of a written advance directive. Consequently, without an advance directive, there can be no grounds for considering euthanasia for a person who, at that time, is no longer able to express a valid "current request". This ethical guideline is in line with the idea - prevalent within Belgian society and enshrined in current law - that euthanasia must always be a response, within a framework of care and solidarity, to an individual request made by a person who states that he or she is suffering from a pathology, and who experiences constant and unbearable physical or psychological suffering, which cannot be alleviated. Euthanasia can never be based on the objectification of a person, nor can it represent a form of "managing" certain population flows, as has sometimes been the case in particularly dramatic and abject historical events⁴.

The question raised in this opinion therefore relates to the conditions under which it is ethically acceptable, when a "current request for euthanasia" is no longer possible, to take into account an advance directive, as regards individuals who are still conscious and whose decision-making capacity and ability to express their will are considered to be irreversibly impaired. The scope of the opinion extends to individuals whose capacity is deemed to be diminished or lost due to a neurodegenerative disease, an accident or a sudden-onset pathology. The opinion looks at the content of the advance directive regarding euthanasia, and the relevant process for drafting and implementing this directive.

Before the ability to make decisions for oneself and to express oneself is severely impaired, potential suffering not only concerns the way in which individuals can actually perceive the development of their pathology, but can also stem from individuals who are in the early stages of illness anticipating what is to come, who do not wish to face the deterioration of their condition beyond a certain point.

Subsequently, while some individuals with impaired capacity to decide for themselves may appear to be struggling with their condition, this is not the case for everyone, which can place carers in a situation of cognitive and emotional dissonance between the instructions in the advance directive, on the one hand, and the verbal and non-verbal signals given by the person in question, on the other. For example, individuals with dementia may have cognitive resources that allow them to react to their environment for a certain time, and as such they retain explicitly manifested emotions, feelings and desires. One of the ethical dilemmas is ascertaining the extent to which their reaction can (still) be considered an expression of their will (e.g. their wish to enjoy life and continue living), even if they have written an advance

⁴ During the Second World War, certain types of population groups deemed to be inferior were subjected to organised killing programmes, disguised under the term "euthanasia" (or "good death" in Greek). [Euthanasia programme and Aktion T4 | Multimedia Holocaust Encyclopedia](#)

directive that contradicts what they now appear to be expressing. This is particularly troubling for family and care teams, who can legitimately wonder whether the wishes expressed by the patient when he or she drew up the advance directive are still valid in this new phase, or whether they have become "*someone else's problem*".

This may explain why, in the Netherlands, the possibility of euthanasia in cases of dementia based on an advance directive is still not widely used, even though the legal possibility exists and many elderly individuals have drawn up a directive⁵. In 2024, 9,958 euthanasia procedures were performed in the Netherlands, including 427 on individuals with dementia who were still capable of exercising their will. Of these 427 directives, only 346 had been evaluated when the report was published: in 340 cases, these were individuals with dementia who were still able to decide for themselves, while euthanasia was only performed 6 times in individuals with dementia who were no longer able to decide for themselves⁶. The reluctance of doctors is linked to the difficulty, if not impossibility, of "doctor-patient" communication at the time of the decision to perform euthanasia, when it is no longer possible for the patient to confirm that the suffering has become unbearable.⁷ Ending the life of a person deemed to be vulnerable may appear, for the doctor, to be against the principle of self-determination vested in this person, even if the doctor theoretically wishes to respect this self-determination until the end, which leads to moral stress and difficulties in interpreting the "open norms" of Dutch law and meeting the criteria of prudence laid down by it⁸.

The main objective of the doctor in this context is to relieve the patient's suffering. Identifying possible suffering in a person with Alzheimer's can be a complex task, not least because this is often based on hetero-assessment (assessment by others, not by the person him or herself). This is another important ethical issue in this debate.

It is necessary to take into account the societal context surrounding neurodegenerative diseases and the way in which impairment of the ability to reason or to express one's reasoning is perceived in our society, as well as typical medical situations and current Belgian and international legislation on euthanasia. As such, these contextual elements will be examined

⁵ Euthanasia was performed in 0.9% of individuals with dementia, while 2.1% of these individuals had requested it (Evenblij et al., 2019, cited in Gastmans, C., van der Steen, J. and Achterberg, W., 2022, Societal and Ethical Views on End-of-Life Decisions in Dementia, in M. Vandenbulcke, R.-M. Dröes and E. Schokkaert, *Dementia and Society*, pp. 233-250. Cambridge University Press & Assessment. Within the population, 6% of elderly individuals have written a directive (Rurup et al., 2006, cited by Gastmans et al., *ibid.*).

⁶ <https://www.euthanasiecommissie.nl/documenten/2024/03/24/index>

⁷ Gastmans, C., van der Steen, J. and Achterberg, W., 2022, Societal and Ethical Views on End-of-Life Decisions in Dementia, in M. Vandenbulcke, R.-M. Dröes and E. Schokkaert, *Dementia and Society*, pp. 233-250. Cambridge University Press & Assessment.

⁸ De Boer, M.E., Coers, D.O, Sizoo, E.M., ten Bokkel Huinink, D.M.J., Leget, C.J.W., Hertogh, C.M.P.M. and the DALT project group (2025). Seeking consensus on dilemmas related to euthanasia in dementia based on advance directive: a Delphi study from a medical, ethical and legal perspective. *Journal of Medical Ethics*, 51, 593-602. doi:10.1136/jme-2024-110276

first. This will be followed by a description of various ethical problems, illustrated by different situations. The ethical principles and values at stake will then be discussed in order to form the basis of the Committee's position on the ethical question posed. The opinion will conclude with recommendations.

2. Contextual elements

2.1. Social context

2.1.1. Fear of dementia in society

At the start of this section, the Committee wishes to highlight the fact that dementia is presented here as a typical case of the situations in which the ethical question it is investigating is raised, but it draws attention to the fact that this opinion is intended to cover all pathological situations that may lead to a similar impairment of the capacity to decide for oneself.

Due to the ageing of the population, dementia is becoming a very common condition that prompts a lot of fear and emotions. According to figures from Sciensano⁹, dementia accounted for around 9% of deaths in Belgium in 2019¹⁰. The risk of a 65-year-old developing dementia during his or her lifetime is around 1 in 20; for an 85-year-old, the figure is 1 in 5¹¹. There were an estimated 212,000 individuals with dementia in Belgium in 2018¹². The WHO predicts that this figure will continue to rise¹³.

There are currently few (short-term) prospects for new treatments that would have a significant effect on the disease. The possibilities for preventing the disease are also limited on account of the still inadequate understanding of the associated determinants, even if there are some avenues: encouraging social relationships, physical and intellectual activity, good hearing; keeping cardiovascular risk factors under control, etc. The disease evolves over the long term, with a gradual deterioration in cognitive abilities and the onset of symptoms such as forgetfulness, difficulties in carrying out daily tasks, language problems and disorientation. The impairment of these abilities, which for many individuals are essential characteristics of their personality, can lead to anxiety, feelings of shame, isolation and stigmatism. The advanced stage of dementia, when the individual is completely dependent on care, or any

⁹ [About Sciensano | sciensano.be](https://www.sciensano.be/fr/coin-presse/la-demence-devient-la-principale-cause-de-deces-en-belgique)

¹⁰ <https://www.sciensano.be/fr/coin-presse/la-demence-devient-la-principale-cause-de-deces-en-belgique>

¹¹ <https://alzheimer.be/la-maladie-dalzheimer/en-chiffres/>, accessed on 31 March 2025.

¹² Ibid, accessed on 31 March 2025.

¹³ WHO, 2012, Dementia: a public health priority. <https://www.who.int/publications/i/item/dementia-a-public-health-priority>

similar situation linked to another cause, is a terrifying prospect for many patients and those around them.

Due to its medical and psychosocial impact on daily activities, dementia can have a significant influence on the quality of life not only of people suffering from it, but also of family members and informal carers. However, the outcome of quality-of-life assessments for individuals with dementia is generally poorer if the assessment is carried out by family and carers than if individuals with dementia make a self-assessment¹⁴. Statistically, self-assessments of quality of life are influenced to a greater extent by depression, functional decline and polymedication. Hetero assessments by family or carers are influenced to a greater extent by functional decline, any neuropsychiatric symptoms, cognitive decline and the burden borne by close carers¹⁵.

The quality of life of individuals with dementia is determined by the progression of the disease, by individual characteristics such as character and temperament, and by external factors such as quality of care, social contacts, psycho-social resources, financial security, etc.¹⁶

Fear of dementia is widespread in society, possibly due to a strong focus on the final phase, with the prevalent idea of the "separation of body and mind", where the body is no more than an empty shell¹⁷, in a society that attaches importance to reason and individual identity. Some individuals feel that, if they were stricken by dementia, their life would no longer be what they would consider as worth living (see the development of this topic, section 2.3), which may prompt them to choose euthanasia. The highly negative image of dementia causes fear, even though there are other ways of looking at it, and the fact there are many different types of dementia, expressed in very different ways (see medical perspective below).

2.1.2. The social acceptability of euthanasia in cases of dementia or impaired capacity to decide for oneself

The Law on euthanasia from 2002 has led to growing public acceptance of euthanasia over the last two decades, with an increasing number of euthanasia procedures performed (from

¹⁴ O'Shea, L. Hopper, M. Marques, M. Gonçalves-Pereira, B. Woods, H. Jelley, F. Verhey, L. Kerpershoek, C. Wolfs, M. de Vugt, A. Stephan, A. Bieber, G. Meyer, A. Wimo, M. Michelet, G. Selbaek, E. Portolani, O. Zanetti, K. Irving & the Actifcare Consortium A comparison of self and proxy quality of life ratings for people with dementia and their carers: a European prospective cohort study. *Aging & Mental Health* 2020;24: 162-170.

¹⁵ Burks HB, des Bordes JKA, Chadha R, Holmes HM, Rianon NJ. Quality of Life Assessment in Older Adults with Dementia: A Systematic Review. *Dement Geriatr Cogn Disord*. 2021;50(2):103-110. doi: 10.1159/000515317. Epub 2021 Jun 24. PMID: 34167127.

¹⁶ https://www.dementie.be/wp-content/uploads/2018/10/RKD_literatuurstudie.pdf

¹⁷ Van Gorp, B. and Vercruyse, T. *Recadrer et recadrer. Communiquer différemment sur la démence*. Study commissioned by the King Baudouin Foundation, 2011.

around 1,000 in 2010 to 3,991¹⁸ in 2024). At the same time, the societal debate on whether euthanasia can be performed in cases of advanced dementia is becoming increasingly fraught. For example, the *Life End Information Forum* (LEIF) launched an online petition in 2019 calling for a change in the law so that (freely translated) "individuals suffering from dementia who have become mentally incapacitated can receive euthanasia".¹⁹ Over 87,000 signatures have been collected. The informative text of this petition refers to the results of the *Grand Baromètre électoral* (Major Election Barometer) by VTM Nieuws, Het Laatste Nieuws, RTL and Le Soir (2018), which show that a large majority of respondents in Flanders (81%) would like to see a change in the law. By contrast, no majorities were observed in Wallonia and Brussels (49% and 46% respectively)²⁰. A poll carried out in 2025 by *De Standaard* showed that **86% of people in Flanders** are in favour of amending the law (*De Standaard*, 22/05/2025)²¹. Furthermore, **67% of doctors** are in favour of euthanasia in cases of mental incapacity due to dementia (*De Standaard* 11/06/2025).²² In the social domain, there appears to be strong support for extending the law. The wish of many citizens to be able to benefit from an extension of the legal framework can be understood as having more control not only over one's own life, but also over one's own death.

However, it is useful to question such surveys and petitions have validity, as many respondents are poorly informed about end-of-life care options for people with dementia in general, and euthanasia on account of dementia in particular. The current legal framework (detailed below) is also poorly understood: not everyone knows that euthanasia is indeed possible in cases of dementia, under current law, as long as the person still has sufficient cognitive and psychological resources to invoke their legal capacity to make a "current request". For example, in 2024, 56 euthanasia procedures were performed in Belgium for cognitive disorders such as Alzheimer's disease (1.4% of the total number of euthanasia procedures, representing an increase in the proportion of euthanasia procedures for this reason). "In more

¹⁸ Figure provided by the Federal Commission for the Control and Evaluation of Euthanasia (FCCEE). This represents approximately 3.6% of the deaths recorded in Belgium. <https://statbel.fgov.be/en/themes/population/population-movement/deaths>. The FCCEE publishes a biennial report on the data collected, intended for the Chamber of Representatives. <https://consultativebodies.health.belgium.be/en/advisory-and-consultative-bodies/federal-commission-control-and-evaluation-euthanasia>

¹⁹ Petition euthanasia for dementia | LEIF

²⁰ https://www.hln.be/binnenland/8-op-de-10-vlamingen-willen-euthanasie-bij-dementie-als-je-niet-wilsbekwaam-bent-kun-je-geen-euthanasie-meer-krijgen-zelfs-al-heb-je-dat-neergeschreven~adc5db34/?cb=32d0377b-a03d-4242-828f-06da8c3df596&auth_rd=1

²¹ *De Standaard* 22/05/2025: https://www.standaard.be/binnenland/meerderheid-vlamingen-is-voor-mogelijkheid-tot-euthanasie-bij-dementie-maar-hoe-zou-de-wet-dat-regelen/68298925.html?utm_source=hyperlink&utm_medium=referral&utm_campaign=share

²² "Physicians' preferences for their own end of life: a comparison across North America, Europe, and Australia", Sarah Mroz, e.a. *Journal of Medical Ethics* <https://jme.bmj.com/content/early/2025/06/05/jme-2024-110192> in: *De Standaard* 11/06/2025: https://www.standaard.be/binnenland/ook-artsen-zouden-voor-zichzelf-euthanasie-kiezen-bij-vergevorderde-dementie/71004667.html?utm_source=hyperlink&utm_medium=referral&utm_campaign=share

than 75% of cases, euthanasia is performed at home or in a nursing home, underlining the crucial role of GPs both in handling the request and implementing it". (freely translated)²³

Many citizens are not fully aware of the implications in principle or the practical difficulties of changing the law on euthanasia for dementia. A scientific study conducted in the United States revealed that just over half of respondents in a representative sample were *a priori* open to euthanasia or assisted suicide²⁴ for dementia patients, based on an advance directive. Having given their response, the respondents were given a specific, elaborate case study explaining the difficulties encountered, such as only partially recognising family members, an imprecisely worded advance directive, the fact there were no obvious signs of suffering, and the possible need for sedation prior to the administration of euthanasia due to the possibility of physical resistance during the procedure (the person not understanding, at the time, what is happening). Attitudes towards euthanasia were then surveyed again among the same respondents and those in favour decreased significantly²⁵, demonstrating how complex it is to put into practice a sincere wish to allow individuals to have more say over the end of their lives, even in the context mentioned.

This may be the reason why there is more resistance in principle among healthcare professionals, particularly doctors, than among the general public to the possibility of consenting to an advance euthanasia directive in patients whose capacity to decide for themselves has deteriorated, as healthcare professionals are generally more aware of the concrete difficulties posed by such a situation. Studies carried out in Australia, Canada and the Netherlands, inter alia, show that barely a third of doctors and just over half of nurses surveyed are in favour of euthanasia in cases of (advanced) dementia on the basis of an advance directive²⁶, a proportion that therefore diverges from the results of the study cited above, reported by Het Nieuwsblad, which stated that 67% of Flemish doctors are in favour²⁷.

²³ https://organesdeconcertation.sante.belgique.be/sites/default/files/documents/11_rapport-euthanasie_2022-2023-fr.pdf, p. 31.

²⁴ In medically-assisted suicide, the doctor prescribes the lethal substances (barbiturates), but it is the person who wishes to die who ingests them or triggers the infusion that administers them. The difference with euthanasia is that the lethal product is self-administered. Furthermore, in many countries where assisted suicide is legal, there is a significant cost for the individual, unlike euthanasia in Belgium.

²⁵ Mangino, Dominic R et al. Assessing Public's Attitudes Towards Euthanasia and Assisted Suicide of Persons With Dementia Based on Their Advance Request: An Experimental Survey of US Public. *American Journal of Geriatric Psychiatry* 2021; 29: 384 - 394

²⁶ Versijpt J, Cras P, Dewitte L, van Delden J.J.M, Gastmans C. Euthanasie bij dementie middels een voorafgaande wilsverklaring: een reflectie vanuit België en Nederland. *Tijdschr Geneesk* 2022; 78: 292-304 (doi: 10.47671/TVG.77.21.199)

²⁷ Physicians' preferences for their own end of life: a comparison across North America, Europe, and Australia", Sarah Mroz, e.a. *Journal of Medical Ethics* <https://jme.bmj.com/content/early/2025/06/05/jme-2024-110192> in De Standaard 11/06/2025: https://www.standaard.be/binnenland/ook-artsen-zouden-voor-zichzelf-euthanasie-kiezen-bij-vergevorderde-dementie/71004667.html?utm_source=hyperlink&utm_medium=referral&utm_campaign=share

2.1.3. Society, the protector of the life, dignity and autonomy of vulnerable citizens

The Universal Declaration of Human Rights²⁸ enshrines a number of individual rights, including the right to life and the right to freedom. Article 1 recognises that "all human beings are born free and equal in dignity and rights". Life, dignity and autonomy are enshrined in this text as important principles of life in society, principles which may, however, encounter resistance in a discussion on the administration of euthanasia, particularly in the case of individuals suffering from dementia or an impaired capacity to express their will.

Euthanasia or medically-assisted suicide is accepted in a growing number of countries, but the patient's explicit wish is an essential condition. This was how the legislator resolved the tensions between the above-mentioned principles. Euthanasia is therefore not just a question of the doctor-patient bond. The importance that society attaches to social control is evidenced, in Belgium, by the due diligence criteria imposed by law, such as the mandatory opinion of another doctor and the mandatory declaration of euthanasia before the Federal Commission for the Control and Evaluation of Euthanasia.

Reflecting on these principles and finding a balance is made even more complex in the context of protecting vulnerable people, including those who are not or no longer fully capable of making autonomous decisions. Situations should be avoided where, on the basis of external considerations and by taking perspectives that are sometimes prevalent in the population, we come to believe that some lives are less valuable than others. A possible extension of the law could lead to the already predominantly negative image of people with dementia being reinforced, to a life with dementia being further characterised as not worth living, and to people with dementia feeling (even more) devalued and socially "useless", which could make them more likely to opt for euthanasia, not out of free choice but because they have internalised the predominantly negative societal "judgment" on the matter. When they draft a possible advance directive, the individual's negative perception of dementia, perhaps due to a view of society they have internalised, may prompt them to overestimate the expected future suffering and underestimate the quality of life that can be enjoyed with adequate care. It is essential to avoid inducing a certain pressure (likely to be internalised) or even insisting on a moral duty to die.

In considering a possible extension, it is therefore important for the legislator to be aware of the social signal that may be implicitly or explicitly conveyed to people with dementia or cognitive impairment, in the context of the debate on these issues. This demonstrates the

²⁸ <https://www.un.org/en/about-us/universal-declaration-of-human-rights>

need to rethink, at the same time as the legal framework for euthanasia, our relationship to dignity, to a life "worth living", to interdependence, and even our stereotypes about the elderly and old age. Although a person's dignity is inextricably linked to his or her existence and even beyond (see below the ethical principles evoked, section 2), the *feeling* of dignity can depend on the consideration a person receives and the way in which society vouches for his or her dignity. Honneth underlines the fact that the individual's identity is formed through three fundamental types of recognition: affective, legal and social. With regard to the latter, it is a question of being valued for one's abilities, talents and contributions to society; and not receiving it generates contempt or social humiliation.²⁹

Compared to *ageing*, which is characterised by changes in organ function, *old age* refers not only to a number of years lived, but also, according to Corinne Pelluchon, to a judgment (freely translated): "it is the moment when an individual says to himself that he's old, because he feels he's been left out of society" in the eyes of others³⁰. This suggests that society makes value judgments about old age and the phenomena that may come with it, in particular dementia. This can prompt older individuals to feel that they are no longer of any use, that they no longer matter to anyone; that calls into question their place in society and disqualifies them. It is indeed the representations of the ideal human life, in particular the importance attached to reason, independence and performance, which in contrast diminish the value that can be placed on this stage of life. For individuals with dementia, the focus is on what they lack. For Van Gorp and Vercruyssen, it is a question of communicating differently about Alzheimer's disease in society and the media, in order to get the public to change their opinions of this disease, and to bring back the human element in the face of illness and loss³¹.

2.2. Medical perspective

Dementia is a generic term for conditions characterised by a gradual decline in cognitive functions such as memory, thinking, language, orientation and problem-solving. This deterioration affects a person's daily functioning and independence, in ways that may vary from one moment to the next or depending on the context. As such, it is particularly complex for doctors to assess the person's ability to make their own decisions on matters relating to health. Dementia is a syndrome for which there is no cure.

The disease often (but not always) leads to the loss of short-term memory and, subsequently, to the loss of executive functions, i.e. goal-directed behaviour and adaptation to a situation.

²⁹ Honneth, A. (1995). *The struggle for recognition: The moral Grammar of Social conflicts*. MIT Press.

³⁰ Pelluchon, C. (2020). *Réparons le monde. Humains, animaux, nature*. Paris: Payot-Rivages, p. 236.

³¹ Van Gorp B and Vercruyssen T. *Framing et reframing: communiquer autrement sur la maladie d'Alzheimer*. March 2011. Brussels: King Baudouin Foundation. 80 p. ISBN 978-2-87212-634-7. www.kbs-frb.be/publication.aspx?id=277380&LangType=2060 (full text).

Executive dysfunction leads to limitations in daily activities. As the disease advances, the patient's ability to make independent decisions and express his or her wishes also diminishes. The degree of cognitive impairment, i.e. the severity of dementia, is inversely correlated with the level of ability to express one's will. This ability is also contextual and specific to the decision that must be made (see the discussion on the ability to decide in the legal section 1.3.1).

There are various illnesses that can lead to dementia. The consequences of these illnesses can vary in terms of cognitive and behavioural disorders, and consequently in terms of the ability to make decisions and express wishes. They are briefly described here for the layperson, along with other conditions that lead to a sudden alteration in the patient's ability to make decisions for themselves.

Alzheimer's disease, the most common form of dementia, is a progressive illness. The first signs are often when a person has problems remembering things. From the outset, the patient loses memory of personal experiences (episodic memory) or finds it increasingly difficult to keep an eye on the bigger picture. The cognitive decline becomes more and more obvious over time. Language, visuospatial and higher control functions are all affected to varying degrees. Communication can be complicated by difficulties finding the right words, and can even lead to complete loss of language comprehension. Visuospatial disorders include problems with recognising faces (prosopagnosia). Diagnoses of Alzheimer's disease have evolved considerably in recent decades. Cerebrospinal fluid examination and medical imaging (MRI and FDG-PET scan) make it possible to diagnose with more certainty. Absolute certainty is only confirmed *post-mortem* by the presence and distribution of amyloid plaques and neurofibrillary tangles of *tau* protein in the brain. The closest correlation has been observed between cognitive symptoms and the latter neuropathological finding.

At the outset, certain individuals may be painfully aware of their memory loss and cognitive difficulties, an awareness of the illness that can lead to anxiety, frustration and despondency. However, as the disease progresses insidiously, this suffering may wane, or even disappear altogether. Paradoxically, this loss of lucidity can sometimes alleviate the anxiety, but it also makes it more difficult for those around the patient to communicate and understand the condition. The emotional and behavioural experiences of individuals with Alzheimer's are also significantly affected. There may be emotional lability, with sudden, unpredictable mood swings. Anxiety and agitation can arise from confusion, feelings of loss of control and difficulty in grasping the environment. Apathy and social withdrawal may mean that these patients give up on once-cherished activities and social interactions. Repetitive behaviour, such as incessant talking or gesturing, may develop and, in some cases, a loss of inhibition can lead to socially inappropriate behaviour.

Besides cognitive and behavioural problems, Alzheimer's disease has a profound impact on a person's identity and sense of self. The patient may be overwhelmed by a diffuse sense of loss, a feeling that something is not right or that he or she is no longer able to do what he or she used to do. Nevertheless, despite these losses, patients still retain the ability to feel emotions and show affection, especially in response to non-verbal cues. It is crucial to remember that people with this disease are still humans, with fundamental emotional needs. Their dependence on others for everyday tasks gradually increases, which may affect their sense of autonomy and dignity.

Logical reasoning and the ability to make judgments start to deteriorate. This is on top of behavioural problems such as apathy and indecision, and it may be difficult to make clear, informed decisions on specific issues. For example, it has been shown that individuals with Alzheimer's disease make both safe and risky decisions, and fluctuate between the two more frequently than individuals without dementia. Moreover, due to issues with attention and executive functions, sufferers struggle to remember the outcomes of previous decisions when making new ones.

Assessing the specific retained abilities of a person with Alzheimer's disease requires a multidimensional approach that takes into account cognitive, functional, behavioural and social aspects. The aim is not only to measure the decline, but also to identify retained abilities so as to best support the person and adapt the interventions. Knowing a person's interests, hobbies and past routines can reveal specific abilities that may still be present, even if only partially. Adapting the assessments to the person's life story and previous skills can reveal specific abilities that would not be visible on standardised tests.

Huntington's disease is a dominant hereditary disorder characterised by progressive deterioration, in particular in the basal ganglia, of the areas responsible for automatic and learned motor skills. The cause of this disease is an abnormally long trinucleotide repeat (CAG). It first manifests itself in behavioural disorders and changes in character. Depression, irritability, aggression, apathy and obsessive-compulsive behaviours are common symptoms of Huntington's disease. This is followed by an involuntary movement disorder called Chorea, which is characterised by sudden, coordinated jerky movements that resemble dancing. Over time, dementia can develop in some patients: speech problems start, the memory deteriorates, organisational skills deteriorate, psychiatric symptoms appear (obsessive-compulsive thoughts, delusions and hallucinations) and impulse control can falter.

In the case of **Parkinson's disease**, dopaminergic neurotransmission systems are disrupted. More than half the dopaminergic neurons have already disappeared before the symptoms appear. The onset of Parkinson's disease may be due to a combination of hereditary and environmental factors. Unlike diseases such as Alzheimer's or Huntington's, where cognitive

and behavioural disorders may predominate, Parkinson's disease initially manifests itself through motor symptoms. However, it is essential to recognise that cognitive disorders, mental health problems such as depression, anxiety and apathy, as well as other non-motor symptoms, are also common and influence the individual's overall abilities to a significant extent. Parkinson's disease is a clinical diagnosis, where there are abnormal movements together with one of three main symptoms: trembling while at rest, continued resistance to passive movements (rigidity) and/or postural instability. Slow progression and persistent asymmetry in the clinical picture confirm the diagnosis. Automatic motor control is particularly impaired, so the patient has to consciously think about every movement. Slowness of thought (bradyphrenia) is common. Behavioural and emotional aspects should not be overlooked. Depression and anxiety are common comorbidities that can significantly affect motivation and involvement. In addition, cognitive disorders have a major impact on quality of life: problems with memory, attention, planning and spatial perception are particularly problematic for patients. Dementia can also occur in individuals with Parkinson's disease. In such cases, hallucinations and delusions predominate. The assessment of specific retained abilities focuses on identifying cognitive strengths that are not significantly dependent on motor skills, and which take into account the slowing of thought processes.

Frontotemporal dementia (FTD) is a neurodegenerative disease primarily affecting the frontal and temporal lobes of the brain. These areas are responsible for personality, behaviour, language and social perception. As such, the main symptoms of FTD are often related to behaviour and language. Behavioural symptoms of FTD can include personality changes such as apathy, indiscipline or impulsivity, loss of empathy and social awareness, repetitive or compulsive behaviour, difficulty in planning and decision-making, and loss of motivation and initiative. Language symptoms can include difficulty finding the right words (anomia), reduced language comprehension, problems with grammar and sentence structure, inability to speak fluently (primary progressive aphasia), and difficulty reading and writing. Other possible symptoms of FTD include memory loss (although not as pronounced as in advanced Alzheimer's disease), changes in eating habits and loss of executive functions (e.g. difficulty in problem-solving and multitasking).

FTD can be caused by **amyotrophic lateral sclerosis** (ALS). ALS is a neuromuscular motor disease that is sometimes genetic, but mainly sporadic. ALS is caused by a degeneration of both peripheral and central motor neurons. The main problem is a deterioration of the most lateral nerve circuit controlling the muscles (hence the term 'lateral sclerosis'). As a result, muscle mass decreases (hence 'amyotrophy'). Loss of strength is usually the first visible symptom; the patient has often recently suffered from muscle cramps. The extent of the atrophy and weakness varies from one muscle group to another. Electromyography (EMG) is an important test in making a diagnosis. As the muscles controlled by the medulla oblongata weaken, it can become increasingly difficult to make basic efforts: swallowing problems and

malnutrition may mean that tube feeding becomes necessary, shallow breathing may require possibly invasive support, and communication aids may be needed. Cognitive decline is sometimes observed as a result of FTD in the context of this disease (see above). A gradual change in behaviour and personality is then observable, as well as problems with memory and executive function. Spontaneous speech is often impaired, with patients finding it more difficult to find their words and ending up unable to speak (mutism). In this case, problems with decision making are due to disruptions in the ventromedial regions of the *lobus frontalis* in the brain³². Nevertheless, these individuals may have normal results on neuropsychological tests.

A **traumatic brain injury** (TBI) can significantly affect a person's ability to make decisions. The effects vary according to the severity and location of the lesion. The prefrontal cortex, essential for executive functions such as planning and judgment, is often damaged in a TBI. This can lead to impaired judgment, impulsivity and difficulties with abstract reasoning, which hamper decision-making. Damage to the hippocampus, which is responsible for memory, can also impair decision-making. Memory problems and difficulties with prospective memory can limit access to relevant information and make it difficult to plan future events. A TBI can also trigger emotional and behavioural changes, such as depression, anxiety and irritability. These changes can lead to impulsive or emotional decision-making and distort the perception of social cues, thereby affecting social decision-making. A diffuse axonal injury, involving damage to white matter bundles, can slow processing speed and impair attention and concentration, making it difficult to consider different options and make informed decisions. Pre-existing conditions, the side effects of medication, and social and environmental factors may exacerbate problems with decision-making after a TBI. The assessment of decision-making capacity following a TBI requires a comprehensive evaluation of the individual's understanding of the decision, whether they understand the consequences, their reasoning capacity and ability to express a choice.

Like a TBI, a **cerebrovascular accident** (CVA or stroke) can seriously affect decision-making. Here too, the damage caused the brain depends on the area affected. If the CVA affects the prefrontal cortex, the person may have difficulty planning, judging or making rational decisions. They may act impulsively, without thinking about the consequences. A CVA can also damage the parietal lobes, which are involved in a person's understanding of the world around them. This makes it difficult for the sufferer to assess situations and make the right decisions. The limbic system, which manages emotions and memory, may also be affected. This can lead to mood swings and memory problems, with decision-making becoming more impulsive and less rational. Finally, a CVA can affect the thalamus, which filters incoming

³² Damasio, A. R. (1994). *Descartes' error: Emotion, reason, and the human brain*. New-York: Putnam

information. Attention and concentration may then be disrupted, complicating decision-making. Depending on the areas affected, the person may find it difficult to make medical decisions, manage finances or even perform simple daily tasks. It is therefore important to assess the person's ability to understand situations, evaluate the consequences of their choices and clearly express their decision. This assessment is essential to help the person regain his or her independence.

The assessment of the specific skills retained in dementia caused by a CVA, or vascular dementia, requires an individual approach that takes into account the location and extent of the brain damage. Unlike primary dementias such as Alzheimer's disease or FTD, vascular dementia is often characterised by a more sudden onset and a 'stair-step' progression, with periods of stability followed by deterioration after new vascular events. The cognitive profile is also more heterogeneous. The assessment of behavioural and emotional aspects after a CVA is also essential. The screening and assessment of a post-CVA depression, anxiety, emotional lability, personality changes and behavioural disorders (apathy, irritability, impulsivity) are necessary.

Apart from primary dementia, the other neurodegenerative diseases described above, CVAs and traumatic brain injury, a wide range of diseases and medical conditions can impair a person's competence by affecting their cognitive functions, behaviour, state of consciousness or physical abilities. In general, primary dementias are considered to be progressive and irreversible neurodegenerative disorders. However, it is important to underline the fact that there are causes of cognitive decline which are, *a contrario*, potentially reversible if identified and treated in time, such as delirium (acute confusional state). There are various medical conditions that can lead to delirium, such as common infections, certain medications and ionic disturbances.

These conditions can sometimes mimic the symptoms of dementia, which is why accurate diagnosis is so crucial. They may also occur in individuals with irreversible cognitive impairment, which makes interpreting the clinical picture complicated.

2.3. Belgian and international legal perspective

2.3.1. Current Belgian law

The **Law of 28 May 2002 on euthanasia**³³ provides for two scenarios: a "current request", made at the time when it is being considered whether to administer it; and an advance directive, prepared prior to the circumstances in which euthanasia will (possibly) be

³³ Consolidated version of the law: <https://www.health.belgium.be/fr/loi-28052002-relative-leuthanasie>

implemented. In both cases, the request must be made by a person capable of making rational judgments. This law does not provide for a system of personal representation such as that provided for in the law on patients' rights: it is the person him/herself who must make a request for euthanasia, whether "current" or anticipated.

The conditions of application of "current request" are as follows:

- The request must be 'voluntary, considered and repeated', without external pressure, by a person capable of making rational judgments;
- The patient must report constant and unbearable suffering that cannot be relieved;
- The patient must be in a hopeless medical situation, as a result of a serious and incurable condition due to accident or illness.
- The euthanasia is performed by a doctor.

Various formal and procedural conditions ensure that these essential requirements are met.

The conditions for applying the advance directive are very restricted: euthanasia can be performed as soon as the doctor observes:

- that the patient "is suffering from a [...] serious and incurable condition,
- and is irreversibly unconscious
- according to the current state of science" (art. 4, § 2).

The 2024 Report of the Federal Commission for the Control and Evaluation of Euthanasia³⁴ stated that less than 1% of declared euthanasia procedures were carried out on the basis of an advance directive (19 in 2023 and 19 in 2022, with this figure dropping to 9 in 2024).³⁵ "The majority of conditions suffered by these patients were malignant tumours or cerebrovascular conditions (cerebral thrombosis and haemorrhage)."

In the current wording of the law on euthanasia, euthanasia cannot be performed on individuals suffering from dementia if their ability to decide for themselves is impaired. This is also the case if the ability to make decisions for oneself is impaired by another pathology, without them being in a situation of irreversible loss of consciousness. Indeed, individuals suffering from dementia or another pathology that has resulted in them losing their capacity to decide for themselves are not or no longer considered capable of making a "current request", and they are not in a situation of irreversible unconsciousness, the condition currently laid down for administering euthanasia on the basis of an advance directive.

³⁴ <https://consultativebodies.health.belgium.be/en/documents/euthanasia-publication-2024-figures-euthanasia-belgium>

³⁵ <https://consultativebodies.health.belgium.be/en/documents/euthanasia-publication-2024-figures-euthanasia-belgium>

It should be recalled that under the law, neither the "current request" nor the advance directive is binding (art. 14). No doctor is obliged to perform euthanasia, and no other person (nurse, pharmacist, etc.) is obliged to take part in it by virtue of his or her freedom of conscience. If the doctor refuses (invoking the conscience clause, always on an individual basis³⁶), he or she must inform the patient or any confidant, in good time and no later than seven days after the request is first made, specifying the reasons for the refusal. He or she must then refer the patient or confidant to another doctor designated by the patient or confidant. He or she must also provide the patient or confidant with "the contact details of a centre or association specialising in the right to euthanasia" and, at the request of the patient or confidant, communicate the patient's medical file to the doctor designated by the patient or confidant within four days of this request (article 14, paragraphs 5 and 7).

The **Law of 22 August 2002 on patients' rights**³⁷ provides for various mechanisms for expressing one's wishes in advance, in view of possibly being incapacity in the future to decide for oneself:

- Advance directive³⁸: the written registration, whether on paper or electronically, of the patient's wishes in the event that the patient is no longer able to decide for him/herself: healthcare professionals are obliged to respect the advance refusal of a given intervention and must take into account any other wishes that may have been communicated.
- The representation of the patient:
 - o designation of the proxy,
 - o possibly a personal administrator appointed by the justice of the peace,
 - o cascading representation: cohabiting spouse, legal cohabiting partner, de facto cohabiting partner, adult child(ren), parent(s) or adult brother(s) or sister(s).

The representative must exercise the patient's rights "in the patient's best interest and in accordance with the patient's expressed values, current and future care preferences and life goals". He or she must "involve the patient as much as possible and in proportion to the patient's ability to understand" in the exercise of their rights (art. 14, § 1, para. 2).

³⁶ Conscience clauses are purely at the individual level, not the institutional level. Law on euthanasia, art. 14, para. 4: "No written or unwritten clause can prevent a doctor from performing euthanasia under the legal conditions".

³⁷ Consolidated version: <https://www.ejustice.just.fgov.be/eli/loi/2002/08/22/2002022737/justel>

³⁸ Advance declaration of wishes, which may include wishes and/or refusal of specific interventions, not to be confused with the advance directive provided for by the law on euthanasia and described above. With the exception of this section on the patient's rights, the advance directive referred to in this opinion is the advance request for euthanasia.

- The confidant, who assists the patient in exercising his or her rights as a patient. The patient determines the extent of the confidant's powers (art. 11/1), which may include assistance in exercising rights to information, consent, consultation and copying of the file. If necessary, the confidant can inform a healthcare professional that there is an advance directive. The confidant never represents the patient, but simply assists him or her in exercising his or her rights, as long as he or she is capable of doing so.
- Advance care planning, a concept introduced into the law on patients' rights in the context of the revision that took place in February 2024, which is defined as the "ongoing process of reflection and communication between the patient, the healthcare professional(s), and at the patient's request, family, with the aim of discussing current and future values, life goals and care preferences" (art. 2, 5°). Advance directives and possibilities at end-of-life, such as palliative care and euthanasia, which were possible even before advance care planning was enshrined in law, are therefore a natural part of the dialogue process that encourages decision-making at a time when the patient is no longer capable of expressing his or her wishes. As such, since the amending law of 6 February 2024³⁹, the law on patients' rights provides for the following:

(1) a discussion during which the healthcare professional informs the patient of his or her state of health and the likely evolution, and where he or she inquires about the patient's situation and current and future healthcare preferences (art. 7, § 2);

(2) at the patient's request, a consultation with the patient's family designated by the patient and a multidisciplinary consultation with the team (art. 4/1);

(3) advance care planning is organised and the patient's goals and values are taken into consideration (art. 5). The patient can register their wishes in the form of a "positive" (wish) or "negative" advance directive (refusal of a specific intervention, which must be respected by the healthcare professional) (art. 8/2). The healthcare professional takes account of positive advance directives, but is never obliged to implement them, on account of their diagnostic and therapeutic freedom⁴⁰, whereas patient refusals⁴¹ in connection with an act of care are binding.

The provisions relating to representation stipulate that the patient's rights shall be exercised by a representative insofar as the patient is unable to exercise them him or herself and for as

³⁹ <https://www.health.belgium.be/fr/professionnels/professionnels-sante/sante-humaine/qualite-securite-soins-sante/droits-patients/droits-patient>

⁴⁰ Law of 22 April 2019 on the quality of healthcare practice, art. 4. <https://refli.be/fr/lex/2019041141>

⁴¹ If it is an advance refusal, it must relate to a specific intervention.

long as he or she remains in this situation. The patient must be involved, as much as possible and in proportion to their ability to understand, in exercising their rights. The assessment of the extent to which the patient's rights can be exercised by the patient him/herself is the responsibility of the relevant healthcare professional, if possible in consultation with the patient and the representative. The aim is therefore to reach a joint decision. Provided the patient has drawn up an advance care plan, this will be used as a guide for the representative, who will also take into account the patient's preferences and life goals, of which he or she has been informed in other ways, for example by the patient him or herself previously, by the confidant or by family members.

However, the request for euthanasia is strictly personal, and cannot be made by a representative: only the patient can request it. As such, the extra-judicial mandate whereby a notarial deed can be used to appoint a proxy who may be responsible for the administration of the person could not, in the current state of the law, pertain to a request for euthanasia. There is some debate in specialist legal literature as to whether this limit should be changed.

For example, according to C. Lemmens⁴², it should not prevent a request for euthanasia being included in an extra-judicial mandate⁴³, provided that this request for euthanasia and the context in which it must be implemented are expressed sufficiently explicitly. In such cases, the proxy does not request the euthanasia. They simply present the application drafted by the declarant/patient him or herself. As such, an advance euthanasia directive could be made by a patient's proxy, provided that it is detailed and sufficiently explicit regarding the circumstances and conditions of implementing the euthanasia, and that it is resolutely the expression of the patient's own will and not that of the proxy.

In such a scenario, in the wake of the reform of the law on patients' rights by the law of 6 February 2024, it would seem necessary or at the very least advisable that, if the patient is irreversibly incapable of confirming his or her wishes:

- The advance euthanasia directive must be laid down in writing with reference to the patient's wishes for future health care, health objectives and life goals.
- Advance care planning is organised through a one-on-one discussion with a competent healthcare professional⁴⁴, which means that the patient's wishes in terms of and health/quality of life values can be recorded, while respecting the ethical principles of patient autonomy and self-determination.

⁴² C. Lemmens, *Planification anticipée des soins et déclarations family à la fin de vie*, Wolters Kluwer, coll. Droit notarial, 2020, pp. 121-122 and references cited.

⁴³ The extra-judicial mandate is different from the Patient's Rights mandate under article 14 of the law of 22 August 2022 on patient's rights, discussed above.

⁴⁴ G. Genicot, *Droit médical et biomédical*, Larquier, coll. Fac. dr. Uliège, 2nd edn, 2016, p. 794

- This advance care planning can be a reasoned expression of the patient's wishes. It allows the patient, assisted by a confidant, to express his or her values, to indicate what he or she considers to be the most serious restrictions on his or her quality of life, and to describe in advance the physical and/or psychological state that would constitute unbearable suffering on their part, which, if the scope of the advance directive were enlarged, would trigger the implementation phase of the euthanasia procedure.

The dynamic and evolving nature of the patient's motivations, emotions, values and approach to what is a "worthwhile life" means that it is advisable to organise multiple one-on-one discussions, involving the proxy, the confidant and the patient's family and friends in the process, as the patient's capacity to make rational judgments deteriorates.

According to the current text of the law, any doctor in Belgium who performs euthanasia on a person suffering from dementia on the basis of an advance directive, even if the patient specifies wishes in an advance directive relating to treatment or during advance care planning, runs the risk of prosecution (law on euthanasia, art. 13/3).

To understand the spirit of the above-mentioned laws on euthanasia and patients' rights, we need to differentiate between *legal competence* and *decision-making capacity*. **Legal competence** refers to the capacity, based on a legal provision, to perform legal acts autonomously. In the present case⁴⁵, legal incapacity is defined by the justice of the peace as the incapacity of an adult person who, due to his or her state of health, is totally or partially unable to manage his or her own financial or non-financial interests, and who must therefore be the subject of a judicial protection measure (art. 488/1 of the Civil Code and, with regard to judicial protection, articles 492 et seq.). A person suffering from dementia or long-term cognitive incapacity as a result of illness or accident may therefore be assigned an administrator of property to represent them in managing their assets, but also, under certain conditions, a personal administrator to represent them in matters of patient rights. However, if the person protected has been declared incapable, the request for euthanasia is one of the acts that "cannot be the subject of assistance or representation by the administrator" (art. 497/2, 18°, Civil Code).

There is often a certain tension between what the law stipulates and what is feasible in practice. Indeed, many doctors will understand this concept of capacity to mean **the cognitive ability to decide for oneself, or the ability to express one's will**. However, these must be strictly differentiated from legal capacity. It is this cognitive capacity that must be determined by the doctor, and which is considered in this opinion, and elaborated further below.

⁴⁵ This excludes minors, who still have legal incapacity due to their minority.

In order to make a valid request for euthanasia, the requesting patient must be considered (assessed) by the doctor as capable of deciding and expressing his or her will, in one way or another. As such, if individuals suffering from dementia or with other limitations are deemed capable of expressing their will to decide on medical interventions, they can validly make a "current request" for euthanasia - which can be implemented if they meet all the other conditions set out in the law of 28 May 2002.

A person's capacity to express his or her will on a specific question involves interconnected cognitive, social and ethical elements, and is a prerequisite for exercising autonomy and freedom of choice. Exercising this right to choose freely in a given medical context depends on the person's ability to decide for him or herself. Indeed, the capacity to decide for oneself must always be considered in the context of the decision to be made. If someone expresses a particular wish, it is crucial to check whether that person is capable of making a decision on the matter. As such, a person suffering from dementia has the right to communicate his or her request for euthanasia, but the doctor must verify whether the person is capable of opting for euthanasia for him or herself. In order to be capable of making a decision for oneself, an individual must understand the information relevant to his or her decision, be able to think hypothetically about the advantages and disadvantages of his or her choice, and be able to apply the consequences of that choice to his or her own life.

Dementia is marked by the development of multiple cognitive problems, including memory loss. Cognitive problems lead to impaired social or professional functioning, and imply a significant decline from a previous level of functioning. As the disease progresses, dementia also impairs a person's capacity to express their wishes regarding important issues such as a request for euthanasia. The law stipulates that it is up to the doctor to assess at what point a person who is legally capable no longer has the capacity to decide for him or herself in matters relating to his or her health, which involves a complex assessment, including of cognitive faculties, but not only that, as highlighted by Neelke Doorn,⁴⁶ who argues that decision-making capacity can be seen as a multi-level phenomenon:

- First level: a spectrum of competences - cognitive, emotional and social - such as the capacity to empathise, a sense of social relationships, etc.
- Second level: the relationship to these skills, i.e. the capacity to understand and appreciate the meaning of information for the individual situation, and to apply this

⁴⁶Doorn, N. (2009). *Wilsbekwaamheid: weldoen, autonomie, identiteit*. Boom.

Doorn N. (2011). Mental Competence or Capacity to Form a Will: An Anthropological Approach 1. *Philosophy, Psychiatry, & Psychology*, 18(2), 135-145. doi: 10.1353/ppp.2011.0025

understanding to the individual reality. This presupposes that the individual has sufficient self-knowledge and awareness of their illness.

- Third level: decision-making capacity throughout the individual's life: what has always been the person's attitude to life? What is their "life project"? What values have they always cherished? How have they coped with difficulties? Do they take responsibility for their own life?

It should be reiterated that there is no valid instrument for measuring this capacity in a perfectly objective way⁴⁷. The *MacArthur Competence Assessment Tool for Treatment* is often used to assess an individual's capacity to consent to treatment via a semi-structured interview, in particular in patients with dementia⁴⁸. The criteria of Grisso and Appelbaum are also often used to assess a patient's cognitive capacity in making health choices⁴⁹. In order to be able to decide for themselves on matters relating to their health, individuals are expected to receive and understand information, to reason, to evaluate the consequences of different options and finally to express their choice, verbally or non-verbally; besides these criteria, we can add the fact that the person must be able to resist possible influences or pressure and keep this choice over time⁵⁰. In the case of a request for euthanasia, the request must be made in writing (if the person is unable to write, the request is written by a third party who has no material interest in the person's death, in the presence of the doctor) and, for the "current request", pertain to the current situation. The individual must have received and understood all the information beforehand. The doctor will inform the patient of his or her state of health, as well as possible treatments and alternatives, and will do their utmost to ensure that the patient understands. In the case of a "current request", the doctor must "reach, together with the patient, the conclusion that there is no other reasonable solution regarding the patient's situation and that the patient's request is entirely voluntary" (art. 3, § 2, 1°, of the law of 28 May 2002 on euthanasia).

⁴⁷ Teresa Lim, Deborah B. Marin, The Assessment of Decisional Capacity, *Neurologic Clinics*, Volume 29, Issue 1, 2011, Pages 115-126. <https://doi.org/10.1016/j.ncl.2010.10.001>.

⁴⁸ T. Grisso and P. S. Appelbaum, *MacArthur Competency Assessment Tool for Treatment (MacCAT-T)*, Sarasota, Professional Resource Press, 1998; P. S. Appelbaum and T. Grisso, *MacCAT-CR: The MacArthur Competence Assessment Tool for Clinical Research*, Sarasota, Professional Resource Press, 2001

⁴⁹ Appelbaum, P.S. et Grisso, T. (1988). Assessing patients' capacities to consent to treatment. *N Engl J Med.* 319(25),1635-8. doi: 10.1056/NEJM198812223192504

⁵⁰ G. Genicot, The law and bioethics of end-of-life decisions in Belgium, in *The Law and Bioethics of End-of-Life Decisions*, R. Bercea, A. Reichstein and A. Vertes-Olteanu (eds.), Intersentia, coll. Vertes-Olteanu (eds.), Intersentia, coll. Ius Comparatum, 2024, p. 143

2.3.2. Example of Dutch legislation

Dutch legislation on euthanasia, enshrined in the law on Termination of Life on Request and Assisted Suicide (WTL, *Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*), has provided an essential framework for the practice of euthanasia since it came into force in 2002. This law decriminalises euthanasia, subject to strict conditions, which are monitored by five regional euthanasia review committees (RTE, *Regionale Toetsingscommissies Euthanasie*⁵¹). The annual reports of the RTE provide an overview of the assessment and review processes.

The law has not been amended in the Netherlands, as the original text provided for the possibility of an advance written request. Following a judicial decision upheld by the highest court in 2020, it was held that a doctor could carry out euthanasia on the basis of an advance request, and that the law did not require the doctor to obtain confirmation from the patient of his or her request for euthanasia before performing the procedure. It should be noted that a doctor who agrees to perform the procedure must comply with all the precautionary criteria laid down by law. Only after consultation with the health professionals who attended the patient at the time he or she wrote his or her request, with those who attended him or her afterwards, and with the next of kin, while continuing to talk to the patient to the extent possible, will the doctor take this step.

Below is a review of the latest annual reports of the RTE, covering the years 2022, 2023 and 2024, with a specific focus on euthanasia procedures implemented on the basis of an advance directive. The growing concern in society for patient autonomy at the end of life, as explicitly mentioned in the 2023 annual report, means that a detailed analysis of the role and application of advance directives in the domain of euthanasia is crucial.

Over the past three years, there has been a steady and significant increase in the number of directives requesting euthanasia in the Netherlands. The table below provides a clear overview of these developments:

Year	Total number of directives	Increase over previous year (%)	Percentage of total number of deaths (%)
2022	8,720	13.7 (compared with 2021)	5.1

⁵¹ <https://www.euthanasiecommissie.nl/documenten/>

Year	Total number of directives	Increase over previous year (%)	Percentage of total number of deaths (%)
2023	9,068	4 (compared with 2022)	5.4
2024	9,958	4 (compared with 2022)	5.8

Although the exact reasons for this rise are still unclear, and there are no scientific studies to allow in-depth insight, patient autonomy appears to play an important role. The rise can be interpreted as reflecting the growing social acceptance and normalising of euthanasia as a legitimate choice at the end of life. However, it also raises fundamental questions regarding the limits of the "open standards" provided for by the WTL, i.e. the flexibility left to judges, doctors and review committees to interpret and apply the law to specific cases, and the extent to which the law can evolve without losing its strictly regulated character, as some critics suggest. This highlights the tension inherent in the practice of euthanasia in the Netherlands.

Performing euthanasia, on the basis of an advance directive, on patients who are unable to express their wishes, is a specific and ethically complex element of Dutch euthanasia practice. For 2022, the available sources do not provide specific figures for cases of euthanasia performed exclusively on the basis of an advance directive in patients unable to express their wishes. The table below gives an overview of the figures:

Year	Euthanasia on the basis of an advance directive (decisional incapacity)	Dementia (with decision-making capacity retained)	Accumulation of age-related problems	Mental disorders
2023	9 (8 cases of advanced dementia, 1 case of cerebral haemorrhage)	328	349	138
2024	6 (advanced dementia)	340	397	219

The Law on the Termination of Life on Request and Assisted Suicide (WTL) lays down six rigorous criteria that a doctor must meet. In the case of euthanasia on the basis of an advance directive in patients who are unable to express their wishes, the criteria of "unbearable suffering with no prospect of improvement" and the interpretation of the patient's "voluntary and carefully considered request" are particularly complex to assess. The advance directive must be clear regarding the circumstances in which the patient wants to have euthanasia carried out, and there must be no indication that they have withdrawn their request.

The main context in which advance directives are used for patients unable to express their wishes is clearly advanced dementia, with 8 cases in 2023 and 6 in 2024. In addition, in one case in 2023, the cause was a haemorrhagic CVA. This underlines the role of the advance directive for patients who, due to the progression of their illness, are no longer able to verbally make a "current request for euthanasia". The advance directive is designed to extend the patient's autonomy, so that his or her previously expressed wishes can be respected, even after he or she has lost the capacity to make his or her own decisions in this area.

Euthanasia on the basis of an advance directive in patients who are unable to express their wishes, primarily suffering from advanced dementia, still represents a minority, but ethically and legally crucial segment, of all reported cases. The figures are low, which underlines the inherent complexity of these cases and the strict due diligence criteria applied by the RTEs.

The figures for dementia (at least partial impairment of decision-making capacity) and the accumulation of age-related disorders are significant in the context of the general practice of euthanasia. As regards psychological problems, although advance directives can play a role in this respect, they are not specifically mentioned in the available information on decision-making incapacity in this context.

The RTEs play a crucial role in ensuring that euthanasia procedures are duly adhered to, in particular in complex cases where an advance directive is the basis of the decision. Despite their growing number, the percentage of reports of euthanasia deemed negligent is still very low (13 in 2022, 5 in 2023, 6 in 2024). The information available does not point to any specific negligence directly and exclusively related to the interpretation or application of the advance directives themselves. The negligence reported is more general and may be partly relevant in the context of advance directives. Although the total number of cases of negligence is still low, the nature of the negligence reported is changing. In 2023, the focus was on aspects of consultation and the lack of precaution in cases of psychological suffering. In 2024, more emphasis was placed on "appropriate medical care" when the procedure was performed, including complications, incomplete emergency kits and inadequate verification of the extent of the coma. This change may be due to the RTEs focusing more on the technical and medical-practical implementation of euthanasia, in addition to the ethical and legal assessment of the request. It may also be a reaction to specific incidents or lessons learned in the field. This is

relevant in cases where there are advance directives, as implementation can be particularly complex in patients who are unable to express their wishes, in the absence of verbal feedback.

The RTEs⁵² emphasise that the law on euthanasia is a "compromise" that needs to evolve over time. Thanks to the law's "open standards" - in particular with regard to suffering which is unbearable in a hopeless medical situation - the review committees feel that the so-called strict limits can be relaxed. This dynamic perspective is particularly relevant in complex cases such as those involving advance directives, where the interpretation of the patient's wishes and the nature of the suffering are crucial. The RTEs are not just a review committee that passively verifies compliance with the law; they also actively contribute to the development of standards for the practice of euthanasia.

2.3.3. Example of legislation in Quebec

Before Canada passed the federal law in June 2016 allowing Canadian adults to request medical assistance in dying, on 5 June 2014 the province of Quebec voted for the Act respecting end-of-life care, introducing medical assistance in dying.

On 7 June 2023, the Quebec National Assembly took another step forward by enacting a framework that will allow patients suffering from serious, incurable illnesses such as Alzheimer's disease to make advance requests for medical assistance in dying⁵³.

The purpose of the Quebec law (art. 1) is now as follows:

The purpose of this Act is to ensure that end-of-life patients are provided care that is respectful of their dignity and their autonomy. The Act establishes the rights of such patients as well as the organization of and a framework for end-of-life care, including medical aid in dying, so that everyone may have access, throughout the continuum of care, to quality care that is appropriate to their needs, including prevention and relief of suffering.

In addition, this Act allows the exercise of some of those rights by patients who are not at the end of life so that they receive end-of-life care in cases where their condition requires it.

⁵² *The statutory standards for euthanasia and the reviews by the RTEs are good examples of the capacity of our democracy under the rule of law to bridge significant social divisions and arrive at a broadly supported solution to a fundamental dilemma. Such a solution is by its very nature a compromise. The challenge is to ensure that compromise does not become set in stone, but instead to let it evolve. The open norms in the legislation allow for this, within the strict parameters set by that same legislation. The RTEs' task is to ensure a balance in this respect, and they have done so since their inception. I have every reason to be optimistic about the future.*" (Annual Report 2024).

<https://www.euthanasiecommissie.nl/documenten/>

⁵³ <https://www.legisquebec.gouv.qc.ca/fr/document/lc/s-32.0001?langCont=en>

Lastly, this Act recognizes the primacy of freely and clearly expressed wishes with respect to care, in particular by establishing an advance medical directives regime.

The new Article 29.1⁵⁴ sets out the requirements for receiving medical assistance in dying if an advance request has been made in accordance with the law. It should be noted that an advance request for medical assistance in dying can only be made by a person of full age and capable of giving consent to care, suffering from a serious and incurable illness leading to incapacity to give consent to care.⁵⁵ Such a request cannot therefore be made by a person who has not yet been diagnosed with such an illness.

The conditions for recognising the advance request are as follows:⁵⁶

- The person must: Talk with a health or social services professional in order to be assisted throughout the process. More specifically, they must identify a physician or specialized nurse practitioner who agrees to assist in completing the request using the form provided.
 - Designate one or two trusted people, if they wish, called “trusted third person”. Their role is to make sure the wishes the person expressed in their advance request for medical aid in dying are known and respected, if all the criteria set out in the Act are met. These trusted people must make sure that health or social services professionals are aware of the existence of the advance request for medical aid in dying and inform them when they observe certain situations.
 - Describe in detail in their request clinical manifestations, such as symptoms, associated with their illness. The manifestations chosen by the person will constitute the expression of their consent to receive medical aid in dying when they have become incapable of consenting to care and provided all the criteria set out in the Act are satisfied.
 - Sign the request form in the presence of: a physician or a specialized nurse practitioner, two witnesses, unless the request is made by notarial act, the trusted third person(s), if any. A witness may not be a minor or a person of full age who is incapable. Nor may they be designated as a trusted third person or act as a physician or a specialized nurse practitioner for the purpose of administering medical aid in dying to the person. When the advance request for medical aid in dying is made with witnesses, the person making the request does not have to disclose its content.
- If the person who wishes to make an advance request for medical aid in dying cannot record it on the form or date and sign the form because they cannot write or are

⁵⁴ Entered into force in October 2024

⁵⁵ <https://www.quebec.ca/en/health/health-system-and-services/end-of-life-care/medical-aid-in-dying/advance-request-medical-aid-dying#c290534>

⁵⁶ [Advance request for medical assistance in dying | Government of Quebec](#)

physically incapable of doing so, another person may do so, in their presence and as instructed by the person.

- To be valid, the advance request must be recorded in a register provided for by law by a physician, a specialized nurse practitioner or a notary. This is where any updates to the advance request can be mentioned and consulted by professionals.

The doctor or specialized nurse practitioner who accompanies the person in formulating his or her advance request must ensure that the clinical manifestations described in the request are medically recognised as being clinical manifestations that can be related to the illness from which the patient suffers, and that they are observable by a competent professional who would have to observe those manifestations before administering medical aid in dying. The competent professional providing assistance to the patient must notify them that the advance request, made in compliance with this Act, will not automatically lead to the administration of medical aid in dying. The competent professional must, in particular, inform the patient of the possibility of withdrawing or modifying the advance request and the applicable terms and conditions for the withdrawal or modification.

This professional must also discuss with members of the care team who are in regular contact with the person making a request, if this is the case, discuss with the close relations of the person making a request or with any other person they choose, if the person so wishes, make sure that the person has had the opportunity to discuss their request with the people they wanted to contact.

Before administering medical aid in dying following an advance request, the physician or the specialized nurse practitioner must be of the opinion that the person meets all the criteria set out in the Act. They must also obtain the opinion of a second physician or specialized nurse practitioner confirming that the criteria set out in the Act have been met. The professional must ensure that the process for administering medical aid in dying continues only where the professional concludes that the patient is exhibiting, on a recurring basis, the clinical manifestations related to their illness that they described in the request, and that the patient's medical state gives cause to believe, based on the information at the professional's disposal and according to their clinical judgment, that the patient is experiencing enduring and unbearable physical or psychological suffering that cannot be relieved under conditions considered tolerable.

If the physician or the specialized nurse practitioner concludes that they cannot administer medical aid in dying (conclusion following application of articles 29 or 29.19), they must inform the person concerned and also inform them of other services that can be offered to relieve their suffering. They must also inform any trusted third person designated in the request any health or social services professional who is a member of the care team responsible for the person. An advance request is not cancelled because a physician or a

specialized nurse practitioner has concluded that they cannot administer medical aid in dying, unless this conclusion results from the refusal expressed by the person to receive such aid.

2.4. Ethical issues and clinical vignettes

As evidenced by the low take-up in the Netherlands of the possibility of implementing euthanasia in a person with advanced dementia pursuant to an advance directive, what seems clear and implementable on paper is often less so in practice. Various ethical issues may arise when the decision is taken to implement the request. These can be summarised and grouped as follows:

- 1) difficulties in interpreting the patient's wishes, as formulated in the advance directive, in relation to the current situation, which may not always exactly match the details in the advance directive;
- 2) the difficulties of drafting an advance directive, which details future wishes and preferences, whereas the person changes over time and experiences, and his or her preferences may therefore also change;
- 3) the tension between the patient's autonomy, as codified in the advance directive, and his or her relationship with others (family and carers).⁵⁷

In general, there are two pitfalls to be avoided when considering implementing a request for euthanasia in a context where decision-making capacity is impaired:

- Firstly, a difference in access to euthanasia between, on the one hand, patients suffering from a neurological condition and, on the other, patients suffering from a non-neurological condition (such as cancer), since the effects (progressive or sudden-onset) of the pathology suffered by the former mean that it becomes increasingly difficult - or even impossible - to receive euthanasia, whereas this is not the case for the latter. This relates to the requirement to verify the person's capacity to decide for themselves, precisely that which is impaired in the case of neurological conditions.
- Secondly, a literal approach to the advance directive, which would mean that it is the sole basis for decision-making. Interpreting it this way could lead to a quasi-automatic application of the advance directive if this possibility was granted in the context of an extension of the current law, without taking into account any signals given by a patient who is not unconscious and continues to have experiences in the context of his or her daily life. It goes without saying that a "bureaucratic" interpretation, in which what is recorded on paper automatically takes precedence over everything else, is completely opposed to the current rationale of the law on euthanasia, which is based on

⁵⁷ Gastmans, C. et al. (2022), op. cit.

reconciling two freedoms: that of the patient requesting it (if necessary through an advance directive) and that of the doctor who receives and accepts the request.

Specific attention must therefore be paid to all the circumstances to which this type of situation may pertain, in order to specify the relevant response.

Clinical vignettes

Complex ethical issues may arise in connection with the "voluntary, considered and repeated" request, the assessment of the capacity to decide for oneself, and the evaluation of whether there is any external pressure, or not.

Fluctuations

A geriatrician treats a lady in hospital whose cognitive abilities fluctuate significantly in the space of a few minutes during a conversation: one moment, she can correctly identify the fact that her memory is failing her, that this makes her very anxious and afraid of what lies ahead; the next moment, she's back "in" dementia and wants to go home because "the children will be home from school" and, a little while later, the doctor can make her laugh with a joke...

Another hospitalised patient shows behaviour that is indicative of frontal but also variable brain damage: one moment, he asks the geriatrician if she wants to marry him; the next, he tells her how sorry he is for what he has become... "I'm nothing any more".

If these patients were to request euthanasia at a time when the conversation about their state of health showed that they still retained certain capacities, the geriatrician would find it extremely difficult to make a judgment as to whether they really wanted it and whether it was long-term wish.

Assessing the capacity to make decisions for oneself, which is important in the context of a "current request", is complex for people with dementia, as their condition can fluctuate from one moment to the next. Nevertheless, a "current request for euthanasia" must be repeated and not change over time.

The *request not changing* is a major point of tension when considering implementing a ("current") request for euthanasia in a person with dementia. The fluctuating moods and opinions of people with dementia make considering the request more difficult. Unlike situations where the patient is in a coma or irreversible unconsciousness, whereas the current law allows an advance directive to be taken into account because the situation is irreversible and it is no longer possible to communicate with the person in question, the situation of

dementia (or any other condition described above, associated with a deterioration in the capacity to decide for oneself) that the person is experiencing does not prevent them from expressing thoughts or feelings, which very often fluctuate. The doctor is therefore faced with a number of signs that can sometimes seem to "contradict" or "undermine" the wishes clearly expressed at other times.

It is therefore essential to continue talking to the person as the disease progresses, and to ensure continuity of information wherever possible. In this way, it can be ensured that the subject is always broached by the same trusted caregiver, that the questions are the same every time, and that family or healthcare providers who know the patient and come into contact with him or her on a daily basis are involved. Knowing the person's life story, including this dialogue in advance care planning, and evoking past and present wishes, provides a "complete picture", to the extent possible.

Request without pressure

A doctor recently diagnosed the onset of Alzheimer's-type dementia in a 75-year-old woman. Her husband always accompanies her to consultations. At every consultation, he brings the conversation back to their fear of deterioration, the degrading nature of dementia and the fact that his wife would be better off writing an advance directive stipulating euthanasia. The doctor repeatedly explains to the husband that there is no point in doing this, as current law does not allow euthanasia for advanced dementia on the basis of a prior request for euthanasia, if there is no irreversible unconsciousness. But the husband continues to insist that his wife go through with it. Finally, the patient writes her advance euthanasia directive. If the scope of the advance directive is extended in the law, when this patient is at an advanced stage of dementia, the doctor may legitimately question whether the patient's advance directive truly reflects her wishes, or whether the patient wrote it under external pressure.

In this situation, the pressure (or influence) may seem direct and obvious; however, ultimately there is still an advance directive written and signed by the person in question, who is still capable of exercising his or her rights. There is no such thing as the complete absence of external influence: everyone is influenced to a greater or lesser extent by the relationships they have with their family and carers. These are important elements to take into account both in the case of a "current request" and in the case of an advance directive.

Moreover, society's view of ageing and loss of cognitive capacity may be a form of internalised pressure. Faced with such a request, the discussions must also focus on the person's viewpoint and fears for the future, and what the possibilities are to humanely care for people with dementia.

It seems important that the anticipated declaration of euthanasia should be drawn up in the presence of a doctor who knows the person, on the basis of repeated discussions, and that the doctor who will have to decide whether or not to implement it should also be as well-informed as possible about the life story and the whole process that has been carried out and discussed. Coordinated care and advance care planning are essential.

Constant, unbearable suffering

A man with dementia has a traumatic wartime past. He has become increasingly anxious since his cognitive decline. At the slightest noise, he hides under the table. He sometimes stays there for hours, in extreme fear. He also looks around anxiously, sometimes screams loudly and is difficult to calm down. The carers do not always understand what triggers this behaviour. He barely eats, is often overly anxious or agitated. Despite the medication-based and non-pharmacological approaches, the carers are unable to control this behaviour. The man is visibly losing weight. His children are completely exhausted and at their wits' end. They can't see their father suffer like this. Within two months, two of the four children have decided to stop visiting him. In any case, their father no longer recognises them and sometimes mistakes them for enemies.

All the members of the team agree that this man has unbearable suffering. After numerous interventions with medication over the course of just over a year, and after the man smashes a window during an anxiety attack in an attempt to escape and jump outside, his sedative therapy was increased. Despite this, when the man is somewhat awake, an increase in anxiety is observable. He no longer trusts anyone, including his family. He refuses to eat anything for fear of being poisoned. Given his increasing need for sedatives, and the fact that he is still extremely anxious when awake, it is decided with the team and the family to put an end to this man's suffering, and palliative sedation is used.

The question of unbearable suffering, which forms the crux of the law on euthanasia, is examined here. This is a criterion for a "current request for euthanasia", and is also compulsory in laws in other countries which authorise euthanasia on individuals with dementia, based on an advance directive, either as a clinically required situation or in the description made by the person drafting an advance directive of the conditions he or she would consider to cause him or her unbearable suffering.

Surveys reveal that many doctors find euthanasia acceptable, based on the idea that they are relieving suffering and that, if there is no longer any suffering, there is no reason to actively end the life. The question is then knowing what this suffering entails and when, and by whom (assuming a patient's cognitive abilities are impaired), it must be considered "bearable" or

"unbearable". In the context of advanced dementia, who can and must assess whether the suffering is unbearable?

In implementing an advance directive (if the current framework of the law is extended), besides the possible question of unbearable suffering endured by the patient, there is the question of how the patient's personality, values and wishes are changing. In this context, it must be decided what to do if a patient with dementia expresses a wish to live, or even resists the procedure, at the time euthanasia is performed.

A sometimes surprising evolution

A 37-year-old man, suffering from early-onset dementia caused by a genetic mutation, had witnessed the disease in his father and repeatedly stated that he did not want the same fate, and therefore wished to end his life at some point. The subject of end-of-life came up several times during the various consultations arranged throughout the course of the illness.

When this young man developed advanced dementia himself, he was admitted to a small-scale family environment for people with dementia. Given his young age, he clearly had the best physical capacities of all the residents, but his dementia meant that he was dependent on others for even simple tasks.

When, at a follow-up consultation, the subject of end-of-life was raised again, he replied that it wasn't necessary "because everything was fine". He couldn't really explain when asked why he had changed his mind.

The day after the consultation, the doctor was called by the carer at the nursing home where he was staying, who asked not to discuss the subject again at the next consultation, as the patient was still agitated after the subject had been broached.

A complex problem that doctors face in implementing an advance euthanasia directive in situations of dementia without unconsciousness, in countries where this is permitted, is the fact it is difficult to assess whether the request should be granted, and if so when. In the case of dementia, the patient's personality changes. That raises the question of whether the dementia patient's wishes correspond to what is stated in the advance directive, or whether it is simply "someone else's problem". The fact that a patient has an advance directive does not therefore solve all the problems. The doctor is sometimes faced with a dilemma: adhere to the advance directive or be guided by the patient's current personality, assess the severity of the suffering and ignore the advance directive. In making this decision, the doctor takes on more (perhaps too much) responsibility, compared to the situation of a "current request", where an autonomous patient can still decide right up to the last moment.

Adjusting to the needs

The brother and sister-in-law of a 76-year-old man who has never had a partner are worried. He is admitted to hospital for the second time on account of unmanageable behaviour in his nursing home - he assaults other residents and staff.

His behaviour is manageable on the ward. The carers notice that when this man is in an environment with more stimulation, he becomes easily agitated. He then tends to approach other patients or carers. In his room, he immediately calms down. He prefers to lie on his bed with a towel over his head. An environment without any stimuli clearly allows this man to find peace. With this approach, there are no longer any recurring behavioural problems.

He is sent back to his nursing home with the necessary advice. Thanks to these measures, there are no longer any aggressive episodes towards staff.

In a scenario where the scope of the advance directive is extended, what would have happened if this man had written an advance euthanasia directive specifying his wish that it be implemented in the event of aggressive behaviour towards others, and due diligence had not been exercised to observe the cause of the behavioural disorder and follow up with the necessary interventions?

Part of the suffering experienced by people with advanced dementia, or felt by those around them, can be linked to a complicated adjustment to the living or care environment. Before euthanasia is considered, pharmacological and non-pharmacological interventions to alleviate behavioural problems and improve quality of life must be explored, so that it can be assessed whether the suffering is constant and cannot be relieved. According to Kitwood⁵⁸, the unbearable suffering in dementia results not only from the disease itself, but above all from the negative social interactions and impersonal care environment in which individuals with dementia often find themselves. These living and care conditions can prompt feelings of shame, humiliation and a sense of worthlessness, social isolation, powerlessness and dependence, and the frustration that goes with them. By adopting a dementia-centred approach and focusing on safeguarding the person's dignity, autonomy and social ties, it is sometimes possible to considerably reduce their suffering.

Behavioural disorders are symptoms of impaired perception, manifested by changes in behaviour, mood or capacities, and are common in individuals with dementia. The onset of these disorders, particularly in individuals with Alzheimer's-type dementia, often has an evolution over time with different behaviours appearing at different stages of the disease. They often lead to the individual being admitted to a nursing home. For example, up to 90% of residents with dementia in nursing homes suffer from behavioural problems. It is important

⁵⁸ Tom Kitwood (1997) *Dementia reconsidered. The person comes first*. Open University Press.

to look for possible underlying and triggering causes of behaviours deemed inappropriate, by systematically exploring the different domains that may be at the root of them: type of dementia, personality, life story, environment, social relationships, side effects of medication, etc. There are symptomatic-only medical treatments which, when combined with scientifically-based non-pharmacological interventions, can in some cases improve quality of life and reduce behavioural problems in individuals with dementia.

This clinical vignette also highlights the difficulty of deciding when the conditions for the advance directive have been met. These conditions are complex to describe with precision. A typical example is that of recognising family, since different situations can arise in practice: the patient may no longer be able to remember their names but still shows signs of recognising the link he or she has with them; he or she may confuse them but recognise them as close or familiar individuals, confuse their status (as in the example of the former soldier who mistakes his family members for enemies), or even be indifferent to them... What does it mean, in this wide variety of situations, to "not recognise one's family"? It is difficult to formulate such criteria clearly and with precision, and even more difficult to interpret the situation with regard to them when the question arises of implementing euthanasia.

A complex reluctance that must be analysed

In 2016, a geriatrician in the Netherlands performed euthanasia on a 74-year-old patient, Mrs. B., who was suffering from advanced Alzheimer's disease. The patient had drawn up an advance directive requesting euthanasia in the event of advanced dementia. In her advance directives, the patient had stated that she only wanted euthanasia "when I feel the time is right" and "when I am still somewhat competent". However, as her dementia progressed to an advanced stage, there came a time when Mrs B. was no longer really able to express her wishes when the euthanasia was to be performed.

After an initial attempt to implement her advance directive had been halted due to strong objection from the patient herself - it was unclear whether this objection related to the euthanasia as such, or whether it was due to fear of the needle - the geriatrician feared that, because Mrs B. was agitated, she would again resist the euthanasia. As such, before administering the euthanasia medication, the doctor gave Mrs. B. a cup of coffee containing a sleeping pill, as a precaution, without informing Mrs. B. or having obtained her consent, due to her cognitive state⁵⁹.

⁵⁹ This case was the subject of media attention in the Netherlands as the "coffee euthanasia". This premedication without prior consent was criticised by some, as it raised the question of whether Mrs. B. had actually consented to the euthanasia, or whether the sleeping pill prevented her from objecting. The

This situation underlines just how complex performing euthanasia can be for patients with dementia who have explicitly stated their wish to have it administered at some point. This is a major difficulty if they are no longer able to express their wishes, and their behaviour seems at odds with what they have previously stated. These situations raise questions about autonomy, informed consent and the limits of medical intervention.

If, after careful consideration, the carers are about to implement an advance euthanasia directive for a person with dementia, it may be the case that the person refuses or resists the actions that would allow the euthanasia to be performed. How should this resistance be interpreted? It may reflect a wish to stay alive and a refusal of the euthanasia, i.e. an autonomous choice expressed according to the person's remaining possibilities, as well as a fear of the needle or the white coat, or any other problem.

In addition to the patient's suffering and anxiety, abruptly halting the euthanasia process, or forcibly going through with it, are extremely difficult for the patient's family. Premedication is sometimes considered to avoid instances of agitation, anxiety or aggression when the euthanasia is performed. This decision could be discussed in the context of the advance care planning.

However, this approach does not resolve the issue of a possible wish to live, which contradicts the former advance directive.

Conclusion: The ethical question and its scope

It is clear from the contextual elements and ethical issues presented that there is no simple "recipe" for extending the law on euthanasia to individuals whose capacity to decide for themselves is impaired and who are still conscious.

Although these situations do not systematically result in suffering, contrary to the prevailing view in society, the suffering of some individuals is severe. There are medical, organisational and societal solutions, and in some cases, these can alleviate this suffering, but in many situations they do not lead to a satisfactory care outcome for patients, their families and carers. As a result, there are still situations where the current legislative framework and

geriatrician defended herself by saying that she had acted in the patient's best interests, to avoid her feeling fear or panic during the euthanasia. The Dutch Supreme Court ruled that the geriatrician had acted prudently and that a doctor could respond to a written request for euthanasia from a person who was no longer competent. The Court ruled that administering the sleeping pill in this particular case had not been reckless, since the patient had previously requested euthanasia.

scientific knowledge do not provide a solution. The Committee believes that these situations ought to prompt reflection on a possible extension of the law on euthanasia to conscious persons deemed incapable of expressing their wishes.

Performing euthanasia is still a highly sensitive procedure for the carers involved, even when they are deeply convinced that they are responding to a fundamental request from the patient, and that the euthanasia will relieve suffering for which no other acceptable measure can be taken. Resorting to euthanasia is all the more complicated when the patient's wishes can no longer be expressed or confirmed, and when, moreover, these wishes appear to fluctuate. It is even more complex when the circumstances do not give any reliable indication that the person is suffering from his or her situation, or even when the person actively objects to the euthanasia procedure, even though this situation corresponds in every respect to what he or she has identified in his or her detailed advance directive as unbearable conditions which he or she does not want to live through and which justify his or her request for euthanasia. As such, setting certain "limit points" or "conditions" in an advance directive which, once reached, would, in the patient's view, make it desirable to implement his or her request for euthanasia, does not solve all the problems; at least this is what has been observed in countries which have gone down this route.

To avoid "current requests for euthanasia" being made (too) early, and to also take into consideration situations where the capacity to decide for oneself is suddenly and unexpectedly impaired, the possibility of broadening the conditions for implementing an advance directive should be investigated. The ethical problems that arise are the following: is euthanasia justified for a group of particularly vulnerable patients if the criteria cannot be made sufficiently objective? And conversely, is it justified to disregard a person's previously expressed values and wishes, based on an interpretation of their current situation by someone other than themselves?

The question at the heart of this opinion is therefore:

"Under what conditions would implementing euthanasia on the basis of an advance directive be ethically acceptable in conscious individuals whose ability to decide for themselves and express their wishes is irreversibly impaired?"

The scope of the opinion extends to individuals whose capacity is diminished or lost due to a neurodegenerative disease, but also to persons in whom this reduction or loss of capacity occurs as a result of an accident or a sudden-onset pathology. The opinion looks at the content of the advance euthanasia directive, and the process that should accompany its drafting and the reflection on whether to implement this advance directive. Without claiming to resolve all the ethical issues that will arise, the Committee hopes to provide useful guidelines for

legislators and for the individuals (patients, family and healthcare professionals) who will be confronted with such situations.

3. Ethical principles and values

The ethical principles and values set out in this opinion are linked to an appreciation of the value of human life and its integrity, the autonomy and dignity of individuals (in their own eyes and in the eyes of society) and their quality of life. The societal context described above also prompts an exploration of the value of care and solidarity, in a context where the very capacity of individuals with illness to decide for themselves is impaired and, as a result, they can neither request euthanasia when this capacity is too seriously impaired nor request it in advance within the current legal framework of the law on euthanasia. As such, it is the very nature of the disease and its effects that prevents the patients in question - if they so wish - from benefiting from the same legal possibilities as people suffering from a different type of pathology, in which (at least part) of their capacity to decide for themselves and to indicate the nature of their will is retained. This impact of the nature of the disease on access to euthanasia raises the question of equality between patients and the solidarity resources that society aims to mobilise to provide support when this equality is impaired. This questioning of societal resources does not detract from the need for prudence, given the uncertainty surrounding the clinical situations patients may experience, which is why the precautionary principle is also addressed.

3.1. Respect for life and its integrity

Human life is precious and must be respected and protected, as stated in the Universal Declaration of Human Rights⁶⁰ and the United Nations Convention on the Rights of Persons with Disabilities.⁶¹ This culture of protecting life, and its preciousness, conditions the representations and actions of carers and society alike. However, what may have seemed obvious in the past is perhaps less so now that science and technology have led to advances in modern medicine that keeps the physical body "alive", sometimes without taking into account the quality of life saved and/or the meaning that can be found in the hours, days and years of extended life.

The vitalist movement, which is very much in the minority in ethical literature, resolutely defends the principle of human life as inviolable⁶². With increasing attention being paid in ethical debates to the subject as a person and their autonomy, it has become clear that this vitalist principle must find a balance with other principles of equal value (see below). Otherwise, the vitalist principle could become blind to the individual him or herself and to

⁶⁰ <https://www.un.org/fr/universal-declaration-human-rights/index.html>

⁶¹ https://www.ejustice.just.fgov.be/cgi_loi/article.pl?language=fr&lg_txt=f&cn_search=2006121354

⁶² Blondeau, D. (1999). *Ethique et soins infirmiers*. Les Presses de l'Université de Montréal.

what, for him or her, makes sense in his or her own life. Taken to this extreme, the vitalist principle could be turned on its head, leading to the negation of the subject, and even to over-treatment (the attempt to prolong life as long as possible at all costs and using all the medical options currently available, regardless of the quality of life and wishes of the person in question). That is why, besides respect for life, having an additional focus on what makes it integral, on what gives it meaning, would appear relevant and is unanimously supported by the Committee.

The reflection on integrity enhances our understanding of the principle of respect for life, by integrating health promotion, avoiding unnecessary injury or mutilation, proportionality in care⁶³ and what, from the perspective of the person in question, gives meaning to their life. A focus on integrity includes beneficence/benevolence, and means that the quality of life of the subject can be taken into account, and not just the quantitative nature of how long their life is. For Dworkin⁶⁴, integrity is what allows each individual to create his or her own life project, in which there is a vital place for ideals, values, commitments and beliefs. This idea relates to autonomy as the capacity to make decisions. In practice, this vision means helping preserve the patient's values, even when his or her autonomy is diminished: the patient's future must then be considered in the light of his or her whole life, with end-of-life being an integral part thereof. In other words, it is a question of taking into account the way in which the person exercised their autonomy before the decline in their capacity to make decisions for themselves, for example in connection with the process of dementia.

3.2. Autonomy and self-determination

3.2.1. General considerations

The value of autonomy is perceived as primordial, in particular in Western societies that are resolutely individualistic in nature, and is at the heart of various laws, including those on patients' rights and euthanasia. Autonomy as a value, however, came late to the fore in the debate on patient rights: one of the first mentions dates back to 1954 in the USA, and its use as a key ethical principle dates from 1970⁶⁵. According to Durand, autonomy is expressed through the principles of self-determination, inviolability and transparency of information (or "franchise" (openness) as Durand puts it), and is immediately translated into the legal rule of information and informed consent.

⁶³ Durand, G. (2007). *Introduction générale à la bioéthique. Histoire, concepts et outils* (2nd ed.). FIDES.

⁶⁴ Dworkin, R. (1994). *Life's Dominion. An Argument about abortion, euthanasia and individual freedom*. Vintage Books, New York.

⁶⁵ Durand, G. (2007), *ibid.*

Autonomy can also be defined, from an ethical angle, as the property of the rational agent to decide for him or herself, which suggests a form of responsibility since the person must also reflect on the ethical character of their decision. It is therefore a question of deploying a person's capacity to "do good", taking into account concern for self, concern for others and concern for each other⁶⁶.

In daily care practice, carers strive to support the patient's autonomy as much as possible. The guidelines "Advance care planning for people with dementia" - which are valid, by extension, for all forms of impaired decision-making capacity - recommend always starting from the assumption of maximum decision-making capacity, as long as the opposite situation has not been demonstrated at any time, and taking into account that decision-making capacity is situated in a *continuum* and that its impairment may fluctuate⁶⁷. People with impaired decision-making capacity are not *ipso facto* immediately and totally incapable of making decisions. Moreover, this capacity - and the autonomy it expresses - also depends on the context: a person with advanced dementia may be deemed unable to make decisions regarding financial matters (for example, selling their home or distributing their assets), but they may still, even at later stages, express whether or not they wish to eat, drink or take part in activities. In the case of a person suffering from dementia, whose mouth is permanently closed when food or drink is offered, it will be considered - contrary to what was sometimes the case in the past - that artificially administering food and fluids is no longer ethically justifiable. Non-verbal signals of this kind can be seen as authentic expressions of a capacity to decide on a given issue, which relates to a general capacity which, although (very) severely impaired, has not

⁶⁶ Voyer, G., quoted in Durand, G., *ibid*.

⁶⁷ Albers G, Piers R, De Lepeleire J, Steyaert J, Van Mechelen W, Steeman E, Dillen L, Vanden Berghe P, Van den Block L., *Wetenschappelijke richtlijn Vroegtijdige zorgplanning voor personen met dementie*: https://palliatievezorgvlaanderen.be/wp-content/uploads/2021/07/richtlijn_VZP_bij_dementie.pdf: p. 29: The continuum between decision-making capacity and incapacity. Decision-making capacity and incapacity lie on the same continuum, which means that a person can only rarely be considered either fully capable or fully incapable of making decisions. The degree of decision-making capacity depends not only on the cognitive faculties, but also on the complexity of the decision that must be made, the number of possible options and the associated consequences. In this way, decision-making capacity can also be bolstered or restored through a conversation, or if suitable information is provided. Decision-making capacity is therefore not a general or permanent feature, but must always be assessed at a given moment, in relation to a specific decision. If a person is fully capable of making a decision, he or she has all the relevant information regarding the situation and is able, at a given moment, to understand the consequences of a given act, situation or decision-making process. Since the diagnosis of dementia cannot automatically be equated with incapacity to make decisions [(ref. 61)], it is important to assess the extent to which a person with dementia retains their general decision-making capacity. The following are the guiding principles to follow with regard to general decision-making capacity in people with dementia: - **start from the principle of maximum decision-making capacity** [(ref. 28, 62)] - GRADE 1C; - do not consider decision-making capacity as a static state, but as a fluctuating variable [(63)], and remain alert to signals of decision-making incapacity - GRADE 1C; - **assess decision-making capacity specifically to the task: for a given decision, at a given time** [(28, 36, 62)] - GRADE 1C; - keep a constant dialogue going with the person concerned and encourage them to participate as much as possible [(64)] - GRADE 1C" (freely translated, emphasis added). These are guidelines validated by BICAM and available on pallialine.be, in which the recommendations have been evaluated according to the *Domus Medicarating* system.

entirely disappeared. In the context of an advance euthanasia directive, these signals can - subject to multidisciplinary consultation among experts (with the participation of family) - be interpreted as a confirmation of this request. Similarly, eating and drinking with pleasure, taking part in or even enjoying activities can also express an elementary wish to live (again)⁶⁸, which may then seem to override the wish in the advance directive not to live a life with certain limitations.

On the other hand, autonomy can also relate to the wish to live according to certain values: those which the subject believes support his or her self-esteem and which remain important for him or her for a very long time in the case of dementia, despite the difficulties that the situation entails. Taking this into account can sometimes help a person with dementia to maintain their quality life, a life that has meaning; it allows them to feel good, here and now. "The identification of autonomy with self-determination, and its subordination to possessing reason, memory and articulated language, betrays elitist criteria that reject all individuals in situations of dependence or who are suffering from cognitive impairments as unworthy."⁶⁹

As such, in medical ethics - in the relationship between patient and carer - respecting the autonomy of others not only means appealing to their capacity for self-determination, but also supporting this capacity for self-determination in defining a life worth living⁷⁰, while ensuring that this support does not turn into pressure. This makes it possible to understand that there is no such thing as complete and absolute autonomy, as the Care ethic teaches, and that there can be degrees in implementing it. What is true for everyone is even more so for individuals made vulnerable by illness, especially those whose cognitive abilities have deteriorated through the disease. Neelke Doorn supports this vision, emphasising that an important role of the doctor is to support the patient's decision-making capacity, which is expressed through their ability to respond to a given situation in a way that is consistent with what he or she values and has valued in his or her life⁷¹.

The principle of respect for autonomy implies both negative and positive obligations. The negative obligation requires that autonomous choices and actions are not subject to controlling or coercive restrictions by others. The positive obligation requires substantial cooperation and solidarity on the part of others, in order to support the individual in developing and realising his or her autonomous choices. In the domain of healthcare, this

⁶⁸ Cf. Federatie Palliatieve Zorg Vlaanderen, *Palliatieve zorg en dementie: levenseindebeslissingen*. Reflectienota, Vilvoorde (2018) - <https://palliatievezorgvlaanderen.be/wp-content/uploads/2021/06/REFLECTIENOTA-%E2%80%98PALLIATIEVE-ZORG-EN-DEMENTIE-LEVENSEINDEBESLISSINGEN.pdf>

⁶⁹ Pelluchon, C., op. cit., p. 250 (freely translated).

⁷⁰ Poisson, C.-E., quoted in Durand, G., *ibid*.

⁷¹ Doorn N. (2011). Mental Competence or Capacity to Form a Will: An Anthropological Approach 1. *Philosophy, Psychiatry, & Psychology*, 18(2), 135-145. doi: 10.1353/ppp.2011.0025

means striving to ensure respectful treatment by faithfully disclosing all necessary information, in a suitable format, gauging and making sure that it has been understood, supporting free will and encouraging autonomous choices. Article 3 of the Convention on the Rights of Persons with Disabilities provides for "respect for the inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons", as well as equality of opportunity. The European Convention on Human Rights, as implemented through the decisions of the Court in Strasbourg, does not resolve the dilemma between the individual's right to freedom and the right to be protected from himself or herself. In this regard, the Convention appears to be closer to the purely rational concept of autonomy. On the other hand, the UN Committee on the Rights of Persons with Disabilities stipulates giving priority to the freedom of vulnerable individuals in their current situation (*now-self*), insisting on the concept of support, at the risk of sometimes forgetting the protective dimension⁷². In this second case, it is the support of others that allows the person with dementia to exercise his or her right to autonomy. This would imply that, in the current situation of the person with a disability - in this case a cognitive disability - it is the possibility of reassessing, confirming or regarding as withdrawn the advance euthanasia directive, depending on the signals given by the patient in his or her current state. This is, of course, the opposite of an interpretation that would prioritise a metaphysical theory of the essence of the "autonomous person" as that which he or she was before the loss or deterioration of his or her capacity to decide for him or herself.

People with advanced dementia or severe cognitive impairment may no longer be able to live their lives according to the values and meaning they have previously lived by. In its opinion no. 14 of 10 December 2001 on ethical rules for individuals suffering from dementia, the Committee already stressed that (freely translated) "autonomy is an ideal, which must remain commensurate with human finiteness, taking into account biological and social determinations".

Accepting the mission, as a carer, to jointly work towards maximum autonomy for the patient therefore implies an ongoing dialogue (such as that provided for by advance care planning), which makes it possible to develop in-depth knowledge of the person and his or her life story. This involves an effort to understand the other person through any signals or indications they may give, whether these indications are explicit or, depending on how the disease progresses, implicit or even indirect, possibly relayed by third parties who are very close to the person in question and able to "interpret" these "weak signals". This approach is now reflected in the law

⁷² ME Baudoin and N Kang-Riou, *Vers un droit à l'autonomie des personnes vivant avec la maladie d'Alzheimer? Gérontologie et Société*, 2017, 39 (154), 45-59. <https://www.cairn.info/revue-gerontologie-et-societe-2017-3-page-45.htm>

on patients' rights, which explicitly provides for advance care planning and ensures that patients must always be involved, to the extent possible, in exercising their rights.

The arguments put forward above show just how complex the decision to end a person's life on the basis of an advance directive can be, if that person is no longer able to confirm his or her wishes and if, during a gradual or sudden deterioration in their cognitive capacity, a change in personality can be felt or observed by those around him or her. The involvement of family members and loved ones is important and inevitable, but it can also give rise to disagreements, as the family bring their own subjective values and fears, which do not necessarily accurately reflect the past and present wishes of the person with dementia. If an advance euthanasia directive can no longer be confirmed (or withdrawn), the question arises as to what should be prioritised: the person's previous wishes when they had full use of their faculties? or what carers and family can interpret from their current behaviours? The opinions on this point differ.

3.2.2. Critical and experiential interests

According to Dworkin⁷³, competent adults have the capacity to think, reflect and make free choices regarding the beliefs, commitments and values that give meaning and purpose to their lives as a whole, that make their lives good lives. In terms of interests, he calls these critical interests. Furthermore, individuals have various kinds of direct experiences in the present that give them pleasure. In terms of interests, he calls these experiential interests. Critical interests stand the test of time: they are still valid when the person in question has become incapable of expressing his or her wishes, is in a coma or even deceased. These include, for example, what happens to his or her assets within the family, his reputation from his or her professional activities, or his or her will. These critical interests can be violated by redistributing a person's assets against their will, dragging their reputation through the mud or disregarding their will. Experiential interests only last as long as the person experiences them.

Like anyone else, individuals with dementia or who have lost the ability to express their will have both critical and experiential interests. Should priority be given to critical interests, made explicit, for example, in an advance directive, or to experiential interests, which seem to come from what the person expresses in the context of certain life situations (such as getting pleasure from eating or taking part in a festive event)? Dworkin gives priority to critical interests, reflecting the personality as it was when the person was "intact". This vision reflects an approach to autonomy oriented towards principles⁷⁴. It combines dignity with autonomy,

⁷³ Dworkin, R. (1994) *Life's Dominion. An Argument about abortion, euthanasia and individual freedom*. New York: Vintage Books, Random House.

⁷⁴ Gastmans, C. et al. (2022), op. cit.

independence and preserving intellectual capacities. In this approach, an advance directive must be drafted as unambiguously as possible. This directive, and advance directives in general, then become a tool that allows people to ensure that their wishes regarding an end of life that they consider dignified for themselves will be respected.

Taking the example of a patient in intensive care who is unable to express his or her wishes, the advance care plan he or she has drawn up with his or her attending doctor, or the directives he or she has left with his or her representative or family, will be taken into account. Limitations of care will be imposed, which may lead to the patient's death. Similarly, in the case of a patient who is still conscious but has become incapable of expressing his or her wishes, and who has drawn up an advance euthanasia directive, the existence of suffering that the patient will have considered unbearable in advance, will be assumed when the time comes.

However, is the person with dementia (*now-self*) the same as the person who wrote the advance directive (*then-self*), or has he or she become someone else? Family members and carers sometimes remark that the person has changed. Contrary to Dworkin's view, Dresser gives priority to experiential interests, which are the only ones that are still important to the person with dementia, since he or she is still capable of experiencing pleasure and pain: "Decisions that affect a person with dementia at a given moment must take into account that person's point of view as it stands at that moment."⁷⁵ (paraphrased). In other words, a person's psychological identity changes over time. While this basic theory enriches the discussion, it is still problematic. It is important to distinguish between the *person* him or herself (with a body and a life story) and the *personality*, which is changeable, especially in the case of dementia. This vision corresponds to a care-oriented approach to relational autonomy⁷⁶: the ethical debate on the end-of-life of individuals deemed incapable of expressing their will is then based on the relational context of care practices, and a dialogic process of communication, interpretation and understanding is established within the care relationship.⁷⁷

Along the same lines of relational autonomy, Jaworska⁷⁸ recognises the presence of critical and experiential interests at the same time in the person with dementia, but qualifies Dworkin's concept of value. For Dworkin, critical interests are based on the ability to see one's life as a whole. Fundamental values are reflexive in nature, and show continuity over time. Jaworska's research shows that individuals with mild to moderate dementia are still able to

⁷⁵ Dresser, R. "Dworkin on Dementia: Elegant Theory, Questionable Policy." *Hastings Center Report*, vol. 25, no. 6, 1995, pp. 32-38.

⁷⁶ Gastmans, C. et al. op. cit.

⁷⁷ Cf. the concept of "interpretative dialogue", see Gastmans, C., 'Kwetsbare waardigheid. Ethiek aan het begin en het einde van het leven', Kalmthout, Pelckmans, 2021.

⁷⁸ Agnieszka Jaworska, "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value", *Philosophy & Public Affairs* 28, (1999) no. 2: 105-138.

appreciate and value certain activities and individuals. For example, listening to music, gardening, yoga, making simple works of art, telling stories, etc. For Jaworska, these values constitute new critical interests. They are not the result of the intense use of reason and reflexivity, but they give meaning to the lives of individuals with dementia. This means that respect for the person's immediate interests does not conflict with their well-being or respect for their autonomy. It is third parties helping individuals with dementia to translate their values into their lives⁷⁹. The question remains to what extent the original critical interests are still valid and whether or not they should be given priority.

3.2.3. The ethics of Care

Despite the usefulness of these different philosophical approaches, an overemphasis on the interests of the individual, whether critical or experiential, risks leading to an atomistic or fragmented conception of the person⁸⁰. This ignores the interdependence described in the ethics of care, in particular by Joan Tronto⁸¹ and Carol Gilligan⁸². These ethics recognise vulnerability as inseparable from the essence of being human, and emphasise our necessary interdependence and the responsibility of care providers. As a result, autonomy cannot be seen as the completely free implementation of enlightened decisions by a perfectly independent and rational person. On the contrary, the implementation of autonomy requires a relationship with and support from other people, and care implies sensitivity to the needs of others, in particular the vulnerable, and using the emotions experienced in the relationship as a fundamental moral guide. In care ethics, autonomy is described as relational and situated, and each person's freedom is exercised through mutual aid, support and relationships⁸³. It should be noted that care ethics do not define a hierarchy of needs or interests (between *then-self* and *now-self*): what existed in the past is drawn on to understand what is now. The approach is rather circular, following the movements or oscillations of the relationship, in a mechanism that enriches understanding for the benefit of the person in question.

3.3. Dignity and equality

Human dignity is often described as intrinsically linked to the human condition, as an inseparable characteristic of individuals. Expressions such as "a dignified death" or "the loss

⁷⁹ Fabrice Gzil, Anne-Sophie Rigaud and Florence Latour, "Démence, autonomie et compétence", *Éthique publique* [Online], vol. 10, n° 2 | 2008, published 7 January 2015, accessed 29 January 2025. URL : <http://journals.openedition.org/ethiquepublique/1453>; DOI : <https://doi.org/10.4000/ethiquepublique.1453>

⁸⁰ Fabrice Gzil, Anne-Sophie Rigaud and Florence Latour, *Ibid.*

⁸¹ Joan Tronto, "Un monde vulnérable. Pour une politique du care", 2009, Ed. La Découverte.

⁸² Carol Gilligan, "Une voix différente. La morale a-t-elle un sexe?", 2019, Flammarion.

⁸³ Cf. Gastmans, C., 'Kwetsbare waardigheid. Ethiek aan het begin en het einde van het leven', Kalmthout, Pelckmans, 2021, p. 208.

of dignity" nevertheless show that the concept is interpreted in various ways at the social level, and that dignity - or rather the perception of dignity by an individual - can be dependent on or affected by what that person experiences. Indeed, that is why violations of dignity are violations of human rights, because they imply a violation, a degradation experienced by the subject, which has repercussions both on him or herself and on the way in which human societies conceive the relationship between the subject and dignity.

Verspieren⁸⁴ also proposes differentiating between dignity in its social sense and dignity in its moral sense. In its social sense, dignity is linked to honours, a status or function, and can therefore be given and withdrawn. In its moral sense, dignity is recognised in a person on account of the qualities he or she displays, such as courage in the face of adversity. In these two senses, dignity is acquired by the individual during their development, and can be lost in certain situations or by displaying certain behaviours. In contrast, dignity as an essential attribute aligns with what was described at the outset, a characteristic linked to the fact of being human, regardless of any merit.

This polysemy has a perverse effect, as it means that certain human situations, such as the loss of independence or the ability to reason, is equated with a loss of dignity. Humanism means recognising every human being as worthy, whatever their condition. But humanism also implies recognising the need for others to feel worthy "in their own eyes", which means taking into account the condition of their life and autonomy that allow them to appreciate themselves as such. Here, autonomy is a prerequisite for dignity, or even the source of it, since each person will interpret a life worth living differently.

Alongside dignity as an intrinsic attribute of the human condition, the conception of dignity as subjectively experienced or conceived therefore needs to be considered. *"If I don't recognise my children anymore, I want to be put to sleep, because living in an advanced stage of dementia is degrading"*. This is the kind of thing individuals are often heard saying. (In)dignity is understood here as a subjective state of what we want or don't want for ourselves. This subjective interpretation of dignity is characterised by the fact that individuals may have very different opinions about it. What one person considers undignified, another finds dignified. These are not the whims of subjects who no longer see themselves as anything other than free and autonomous, but rather it is an almost ontological relationship with what makes it possible to endure life as a human subject. It should be noted, nevertheless, that an individual's subjective perception of their dignity can change considerably over the course of a lifetime. For example, a healthy person in their 30s may consider a state of total dependence to be

⁸⁴ Verspieren, P. quoted in Durand, G. op. cit.

undignified if he imagines himself in that situation, but this may no longer be the case when he is actually in such a state in the future.

Attempting to accurately articulate (i) the principle that "all lives are equally dignified from an ethical viewpoint", on the one hand, and (ii) the principle that individuals are entitled to define, at least in part and *always for themselves*, what a dignified life means in their case, on the other hand, conflicts with the difference in access to the request for euthanasia between people whose pathology primarily impairs their ability to decide for themselves, and those for whom this is not the case until a very advanced stage of their illness (e.g. cancer).

If it is accepted that health care in general only very imperfectly responds to notions of justice, the present opinion questions the response of society regarding different access to the possibility of requesting euthanasia, and the resources it can provide to ensure equality, which has been undermined by the nature of the disease itself.

3.4. Solidarity, inclusion and social responsibility

A solidarity-based society is also an inclusive one, in which the elderly are not reduced to feeling like burdens on account of the costs (pension and medical expenses) or care associated with this stage of their lives. In a solidarity-based society, older people are recognised for what they have contributed and still contribute to the prosperity, wisdom and well-being of society and its members. A solidarity-based society also takes care of people who, for various reasons (physical, mental, financial, etc.) are only able to contribute in part, or not at all, to the functioning of the community, and strives to promote their sense of dignity.

Inclusion requires a long-term process of social awareness and critical questioning of the way our society treats older people in general, and people with dementia in particular. The goal is a form of emancipation, eliminating prejudice against older people, with or without dementia, and recognising the final stages of human life as an integral part of a dignified life.

The feasibility of living with dementia depends in part on the social context. A general social climate of solidarity, generosity and tolerance towards those who are different, or the absence of such a climate, plays a major role in this respect. As such, caregivers send an important social signal when they provide quality care to the person with dementia and their loved ones. This implies a need for adequate funding for dementia care in general, and quality initiatives in line with the needs of people with dementia for palliative care. A structural (permanent), structured and relevant response by society to the needs of part of the population is a concrete sign that the persons in question are included in society in the general sense.

It is also important to demonstrate understanding for the elderly and their families, who are faced with new and difficult choices in the current context. There cannot and must not be any social pressure to steer the decision-making process in one direction or another.

Although the ethical debate concerning the end-of-life of people with dementia mainly focuses on the prudence and responsibility of caregivers concerned with specific situations, residential care facilities also have an important responsibility in this respect. For example, the directors of care facilities have a duty to monitor the quality of care provided to people with dementia in their facilities. The carers also need adequate political support. Moreover, every residential care home must have a policy on palliative and end-of-life care for people with dementia in place, including an ethical framework and procedure for complex ethical cases. An ethical policy ensures that individuals with dementia, their families and carers are taken into account, and that all end-of-life care options can be discussed in a structured way. This policy must be communicated transparently, both internally and externally. According to Rawls, a just society must guarantee the material and institutional conditions necessary for individuals to make autonomous choices between different medically relevant options/interventions⁸⁵, whether these autonomous choices lead them to resort to euthanasia or not. It should be recalled that palliative care and access to euthanasia are not mutually exclusive; on the contrary, they are complementary, sometimes concurrent, modalities that are in line with the best care to be given to a person according to his or her needs and preferences.

3.5. Person-centred care and the assessment of suffering

3.5.1. Person-centred care and the assessment of suffering

It is important to reiterate that the vast majority of ethicists refuse to rank human lives in order of importance, whatever the basis for the ranking. They therefore assign equal value to individuals whatever their competences or limitations during their lifetime.

However, this does not mean that ethics is blind to the way in which people appreciate their life conditions or, to put it slightly confusingly, their quality of life. This concept needs to be handled carefully, as discussing it could give the impression that some lives are less valuable than others, and that there could be a hierarchy between different lives. However, this is not the sense in which it is explored in this opinion. If all human lives have equal dignity, in ontological terms, it is important to take into account the human experience in all its multiple and diverse facets, and in the interdependence of human lives, *taking into account the perspective of the person actually in the situation*. In other words, it is not a question of comparing one human life with another, but of comparing a life lived with what the person in

⁸⁵ John Rawls "A Theory of Justice," 1999, Harvard University Press.

question - who is living it - considers acceptable or desirable. From an ethical perspective, this means that any decisions made must always be based on what the person expresses or has expressed about their own life and their wishes regarding it, by virtue of their autonomy.⁸⁶ The commitment to more person-centred care, with specific focus on the (existential) experience of individuals with dementia, should be supported and developed⁸⁷. This would help preserve and support the quality of life of older individuals, whether or not suffering from cognitive disorders.

3.5.2. The assessment of suffering

Taking into account what a person expresses or has stipulated regarding their own life must prompt us to consider the different types of suffering that may arise when the ability to decide for oneself is lost.

Suffering is a universal human experience that can manifest itself in many different ways, both physically and mentally, and impacts quality of life. It is a feeling of intense pain, sadness, anxiety, discomfort or unease that impairs a person's well-being. *Physical* suffering can be caused by illness, injury, disability or other physical problems. These include chronic pain, nausea, shortness of breath, fatigue and reduced mobility. *Mental* suffering can be caused by psychological problems such as depression, anxiety, post-traumatic stress, bereavement, loneliness, etc. These include feelings of hopelessness, worthlessness, anxiety, sadness, guilt and no longer enjoying life. *Social* suffering can be caused by social problems such as discrimination, exclusion, harassment, violence, poverty or the loss of loved ones. These include feelings of humiliation, injustice, loneliness, anxiety and sadness. Moral, existential or *spiritual*⁸⁸ suffering can be caused by existential questions about the meaning of life, feelings of emptiness, insignificance or loss of connection with the metaphysical or transcendent, or even religious for religious people. These different forms of suffering are often inseparable. The concept of *total pain* was introduced by Cicely Saunders, a British physician and founder of modern palliative care. This concept describes the multidimensional nature of the suffering individuals can be subjected to. Suffering can have a profound impact on a person's life, both in the short and long term. While suffering is an inevitable part of human existence, there are ways of coping with it and reducing its negative impact.

⁸⁶ Blondeau, D. op. cit.

⁸⁷ Cf. An Ravelingien Joke Lemiengre and Simon Malfait "Persoonsgerichte zorg, 15 hefbomen voor zorgverbeteraars", 2025, third edition, Lannoo Campus

⁸⁸ Cf. the consensus definition of the *European Association for Palliative Care* (2011): "*Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.*" See: <https://eapcnet.wordpress.com/2022/03/11/the-eapc-spiritual-care-reference-group-building-on-strong-foundations/>

Physical suffering tends to arouse more immediate compassion than suffering from cognitive decline, or at least appears more "identifiable", whereas suffering due to impaired capacity to make decisions for oneself is harder to consider for those who do not experience it, and can be difficult to express, describe and make comprehensible for those who are suffering. However, this difficulty should not mean that we are more aware of physical suffering and that we underestimate the very real suffering associated with cognitive decline and self-transformation in dementia or any other pathology similarly impairing the capacity to decide for oneself.

Auguste Deter, the woman described by Alois Alzheimer as suffering from an *eigenartigen Erkrankungsprozess der Hirnrinde* (A peculiar severe disease process of the cerebral cortex), described her own suffering as follows: "Ich habe mich sozusagen selbst verloren" ("I have lost myself, so to speak")⁸⁹. People suffering from Alzheimer's disease experience the deterioration of their mental faculties as a gruelling and potentially unbearable process. In the early stages of the disease, suffering may even emerge before the onset of symptoms, which can be perceived by others, but already impacts on the quality of life of the person experiencing it, amplifying their anxiety about the future. On the other hand, there are also patients in a specific form of denial, known as anosognosia (from the Greek "not knowing the disease"), at the onset or during the course of their illness. These people are not aware of their own illness, so it is difficult to know if they are suffering from it.

During the course of the disease, and especially as they approach the end of life, individuals with advanced dementia may experience an increase in other distressing symptoms, such as pain, agitation and shortness of breath, as well as high levels of physical, psychological, social and/or existential suffering, although not systematically. These different types of suffering come on top of the other symptoms described in the medical section, and a phenomenological distinction must be made between these different *experiences*. For a holistic approach to the care of individuals with advanced dementia, it is essential to systematically differentiate between physical suffering (or pain) and other forms of suffering, and to take them all into account according to the concept of total pain proposed by Cicely Saunders.

An important condition for implementing euthanasia on the basis of a "current request" is the presence of "constant and unbearable suffering", which cannot be relieved in any acceptable way; suffering due to an incurable condition or the irreversible consequences of an accident. As such, euthanasia in the context of a "current request" is only carried out when the patient and doctor together reach the conclusion that no other reasonable solution is possible to sufficiently alleviate the patient's suffering. Over several decades, medicine has evolved from

⁸⁹ Alzheimer A. Über eine eigenartige Erkrankung der Hirnrinde. Allgemeine Zeitschrift für Psychiatrie und Psychisch-gerichtliche Medizin. 1907 Jan; 64:146-8

an outspoken medical paternalism, in which doctors gave themselves the right to define what was best for the patient's well-being, to a patient-centred model. This means that unbearable suffering must be determined on the basis of the patient's personal experience. This also means that patients' perceptions must be recognised and respected, even in cases of advanced cognitive and physical decline.

In the scenario where the law is extended to people with impaired decision-making capacity, at least two questions are raised as regards the suffering:

- When, in an advance directive, an individual stipulates a series of conditions or points of reference that characterise a situation he or she does not want to have to go through, and which, in his or her opinion, require euthanasia to be carried out in order to prevent the situation from persisting, this is indeed a phenomenological description of what he or she considers to be unbearable suffering. But should the doctor to act if, despite having met the conditions described in the advance directive, he is confronted with a patient who seems calm or, at any rate, does not seem to be in any suffering? What should he base his judgment on? How can we analyse the discrepancy between what is described as unbearable in the advance directive and what appears to be "tolerated" without any particular signs of suffering?
- When suffering is observable following the loss of the ability to decide for oneself, how can we be sure that this suffering is not due to inadequately supportive or adapted care?

These two situations raise a similar question: what should the doctor base his judgment on? Should factors other than the conditions described in the advance directive be part of the doctor's assessment of whether the patient has constant and unbearable suffering? What contribution, if any, do external factors (such as inadequate care, for example) make to a constant and unbearable state of suffering, and how can we identify this possible contribution? The question here is to what extent suffering becomes unbearable because of the way care is provided (which demonstrates the importance - but also the difficulty - of assessing the quality of care). In the same vein, it is essential to manage any behavioural disturbances that may occur within existing guidelines, to ensure that the observable suffering that seems unbearable is not due to anxiety, loss of bearings, etc., which could be managed by carers. This implies a focus on the now-self. Detecting and preventing suffering in individuals with dementia is essential, particularly in relation to possible behavioural disorders that may indicate underlying anxiety, for which pharmacological and non-pharmacological treatments are available. These may include: treatments that should at least have been tried to alleviate the suffering (such as consultations with a dementia referral doctor, other specialised aids, admission to a geriatric or gerontopsychiatric ward); optimising living conditions that ensure quality of life despite the limitations of the cognitive impairment; the provision of palliative

care; the quality of communication with and treatment of those being cared for, etc. Such holistic, individualised care can sometimes alleviate the suffering, but solutions cannot be found for all dementia patients, and it is not always possible to implement them.

The guideline issued by the Royal Dutch Medical Association (KNMG⁹⁰) stipulates that the assessment of suffering in dementia is based, on the one hand, on the medical assessment of prognosis (estimating the likely course of the person's condition) and, on the other, on the patient's own perception of the suffering⁹¹.

Only the patient can say whether the suffering is unbearable for them. It is up to the patient to clearly indicate what makes the suffering unbearable for them. The physician must be satisfied that the suffering is unbearable in order to accede to a request for euthanasia. This involves a professional assessment of the lack of any prospect of improvement in terms of the unbearable nature of the patient's suffering. Words such as 'understand' or 'empathise' are often used in this context. In order to understand the feeling of unbearable suffering, it is helpful to see the patient's suffering in the light of the patient's life story, medical history, personality, norms and values, and physical and psychological capacity to cope. Since unbearable suffering is a personal experience, the physician must be careful not to judge the patient's suffering based on their own view of suffering. Therefore, it is not about whether the physician would ask for euthanasia in a similar situation, but whether the unbearable nature of the suffering is understandable to the physician from the patient's perspective. The physician must examine all the aspects that together make the patient's suffering unbearable. For this, they are advised to draw on the expertise of other physicians, care providers and/or the patient's relatives. (emphasis added).

What is ultimately the question is what would be necessary to convince the doctor and the patient; and if this question arises so acutely here, it is because the situation examined in this opinion is significantly different from the situations encountered in the current legal framework.

In effect, as mentioned above, the current framework provides for only two situations in which euthanasia can be performed:

- either in the context of a "current request", in which case the patient is logically able to express the reasons for his or her suffering, and to discuss with the doctor how the suffering is constant and unrelievable;

⁹⁰ The KNMG is committed to the quality of medical practice and public health, and is particularly interested in the ethical and legal issues faced by doctors. <https://www.knmg.nl/over-knmg-1/over-de-knmg>

⁹¹ KNMG Standpunt / Beslissingen rond het levenseinde, 2021. <https://www.knmg.nl/download/knmg-standpunt-beslissingen-rond-het-levenseinde-pdf>, p. 29.

- or in the context of an advance directive, which is taken into account when a patient "is suffering from a [...] serious and incurable condition, and is irreversibly unconscious according to the current state of science" (art. 4, § 2, of the law of 28 May 2002). In this case, the person who is no longer conscious is not physically in a position to indicate anything that might appear contradictory to the advance directive.

Neither of these situations, despite being eminently complex, is the same as a situation where a doctor could resort to euthanasia on the basis of an advance directive for a conscious patient, who has previously stipulated (in their advance directive) what appeared to them to be the conditions of constant and unrelievable suffering but which, in reality, once the capacity to decide for himself is lost, may appear to express something quite different. What should the doctor base their judgment on?

In a reflection on the KNMG guideline, De Lepeleire et al. argue that too much emphasis is placed on the doctor's role in assessing the request for euthanasia⁹².

Many aspects of taking prudent action are linked to the possible practice of euthanasia for individuals with dementia on the basis of a written advance directive. Questions arise as to the feasibility of such a procedure. Providing for legislation and establishing a procedure so complex and conditional that it will almost never be implemented seems misleading for the patient and virtually unenforceable for the attending doctor. [...].⁹³

The doctor has considerable decision-making power. He or she must also assess whether the Lepelletier patient's suffering is unbearable and hopeless, determine whether the situation is the same as that described in the request for euthanasia, and whether the patient, in his or her current "now-self" state, is still behind the request for euthanasia (freely translated)⁹⁴.

Suffering is a complex phenomenon which is difficult to assess. Consequently, self-reporting is the most reliable method of determining the intensity and extent of the suffering. As cognitive and verbal communication capacities are often severely impaired in individuals with advanced dementia, it is both useful and advisable to assess suffering in consultation with a proxy, the family, loved ones and carers.

The PAINAD (*Pain Assessment in Advanced Dementia*) scale, the DS-DAT (*Discomfort Scale for Dementia of the Alzheimer Type*), the Abbey Pain Scale, and the Dementia Care Mapping (DCM)

⁹² De Lepeleire, J., Lisaerde, J., Tobback, C., Verhaeverbeke, I., Ghijsebrechts, G., Herweyers, K., Pattyn, I. and Van den Noortgate, N. Euthanasie en dementie: reflectie op het KNMG-standpunt 'Beslissingen rond het levenseind'. TVGG. doi.org/10.47671/TVG.78.22.028 <https://tvqg.be/nl/artikels/euthanasie-en-dementie-reflectie-op-het-knmg-standpunt-beslissingen-rond-het-levenseinde>

⁹³ IB. p. 288

⁹⁴ IB. P. 289

scale all attempt to make objective the observation of suffering in individuals with advanced dementia. These scales mainly measure non-verbal signs, as individuals with advanced dementia often have difficulty expressing their suffering verbally. Using different scales and methods gives a more complete picture of the person's well-being. However, scientific research has revealed major shortcomings in the process of developing scales to assess the suffering in dementia, such as the lack of adequate conceptualisation and operationalisation of the concept of suffering, and the absence of any assessment of the validity of the content. These conceptual and methodological shortcomings have resulted in confusion regarding the demarcation of the concept of suffering, including the similarities and differences between suffering and other symptoms, and the extent to which these can be managed. The preliminary (and cautious) conclusion is that unbearable suffering in individuals suffering from dementia cannot be measured objectively - which is not to say that it cannot be observed or understood based on the clinical expertise of carers and the knowledge of the patient by those close to him or her.

Whether the condition is progressive or sudden, dialogue between the patient, the doctor and, possibly, the patient's family, is a fundamental element. This dialogue must continue over time to avoid, to the extent possible, situations where an advance euthanasia directive, drawn up a long time ago and not discussed thereafter, appears when there is no longer any possibility for the person who drew it up to confirm their wishes, or if the person assesses their situation differently, without discussing it. The dialogue must be maintained for as long as possible, and whenever necessary and possible (some patients are isolated), it must be ensured that it involves several types of actor who can testify to what the patient is experiencing and what is or was important to him/her, in order to ascertain that the suffering is constant and unbearable from the *point of view of a person who is no longer able to express him/herself explicitly and clearly on the matter*. In this process, it is important to differentiate between the burden of suffering for the patient and for family (or carers), and to support each of these actors.

3.6. Precautionary principle and conscience clause

Ending the life of a person who is suffering from dementia pursuant to an advance directive is an act whose seriousness and irreversibility are assessed by the Committee.

The process of drawing up the advance directive and the conditions under which it is received, while a key part of any request for euthanasia, is made more complex in caring for individuals with dementia, not least because the carers cannot, in the present scenario, maintain a dialogue with the person with dementia until the end regarding his or her request for euthanasia, as they would be able to do with a patient who has not lost the capacity to decide for himself or herself in the context of a "current request". Consequently, the request for

euthanasia cannot be confirmed by the person directly concerned, who is still conscious. As such, it is preferable for carers to be extremely cautious, and to ensure adequate protection and support.

Indeed, there is a risk of inaccurate or even incorrect interpretation in such cases, due to the dynamic nature of the situation and the criteria used; in particular the possible evolution between a "*then-self*" and a "*now-self*" and the fact it is impossible to obtain confirmation of the person's wishes one last time regarding the implementation of euthanasia.

The consultation with the patient (when possible), family and carers from the multi-professional team is a guide to acting as cautiously as possible. Another is the attention paid to providing individualised care to alleviate the perceptible suffering. The possibility of consulting experts, and/or seeking the advice of an ethics committee, would also help to support a decision-making process that is always difficult and uncertain.

Linked to this principle of caution is the freedom of conscience of any carer who is not firmly convinced that he or she is acting in the best interests of the patient. Depending on the level of doubt, the carer could invoke their conscience clause⁹⁵ which is already included in the law on euthanasia, which states that refusing to perform a legal act within the scope of his or her competence on the basis of the conscience clause is compatible with professional obligations, provided three conditions are met: the caregiver must inform the patient, refer him or her to a colleague who is competent in the field, and do everything possible to ensure that this does not cause undue inconvenience to the patient in terms of delay and accessibility to health care. If the patient does not have a regular doctor, he or she can be referred directly to a competent euthanasia centre.

It is also important to think about the conscience clause in advance, not to deny its existence, but to understand it better in the relationship with others and put it in its rightful place. With the evolution of science and technology, death has become increasingly medicalised. It can be seen as a failure. For the doctor, as a carer, death must be situated in the natural order of the life cycle. As a carer, but also as a human being, he or she must be able to approach death and the resulting grieving as reassuringly as possible. The doctor's possible fear of death can then fade away, leaving room to accompany the patient to the end, transparently and in peace. This is by taking the time to listen to the patient's story, taking into account his or her

⁹⁵ Wicclair described three main approaches to the conscience clause: the "incompatibility thesis", according to which it is incompatible with the professional obligations of healthcare professionals to refuse to provide a service that falls within their competence; "conscience absolutism", which considers that it should be possible for healthcare professionals to be exempted from performing an act that goes against their conscience, including giving information or referring the patient to a colleague; and the "compromise approach", defended by Wicclair in WICCLAIR M. R., *Conscientious Objection in Health Care. An Ethical Analysis*, Cambridge, Cambridge University Press, 2011, p. 32-34.

autonomy, and moving away from medical paternalism to establish a genuine partnership between patient and doctor. Wherever possible, such a partnership is built over time, throughout the patient's care/life journey.

Addressing the conscience clause within the context of a carer-patient partnership opens up the possibility for the doctor to be accountable for his or her actions, knowing the limits they have set in the conscience clause, but also to respond to the other person by listening and providing support, since the conscience clause cannot be used as a pretext for refusing support.

Timothy Quill has also developed the concept of "preference-based medicine".⁹⁶ His aim in this regard is to replace evidence-based medicine (i.e. medicine based on scientific studies with a high level of proof), which takes little account of the patient's opinion, with a form of medicine that emphasizes the patient's role as a key player in his or her own treatment. This shared-decision approach to medicine highlights the doctor's scientific rigour, while promoting patient autonomy in choosing medically relevant options. By protecting both parties, this avoids the risk that the carer's conscience clause is invoked too quickly.

4. Ethical positions

The ethical question in this opinion develops in all its complexity: how can a society which undertakes to respect (1) all human lives as being of equal value, and (2) what matters to each patient in terms of preferences and life choices within the limits of what is legally and medically possible, meet the expectations of individuals who, on account of a pathology, are facing a current or future impairment of their capacity to decide for themselves, and who, on account of the complex personal suffering created by this impairment (current or anticipated), wish to have recourse to euthanasia at some point in their journey?

Are these individuals obliged to request euthanasia "as quickly as possible" as long as their wishes can be confirmed in the context of a "current request" for euthanasia, or can they, subject to a legal framework that needs to be reworked, rely on the advance euthanasia directive to specify this wish in detail and receive euthanasia at a stage when the effects of their illness are proven and result in unbearable suffering?

⁹⁶ QUILL T. E., HOLLOWAY R. G., *Evidence, Preferences, Recommendations - Finding the Right Balance in Patient Care*, NEJM, 366;18, may 3, 2012, 1653-55.

4.1. Points of consensus

- *First point of consensus: to respond to patients facing an illness that affects their capacity to decide for themselves, who wish to have recourse to euthanasia without having to anticipate it in order to fall within the current legal framework.*

The scope of what is currently permitted by the law on euthanasia for individuals whose capacity to express their will is impaired by the onset of a pathology, inadequately meets the needs of some of these patients. Furthermore, a large part of the public are unaware of the restrictive conditions that currently exist for implementing euthanasia on the basis of an advance directive. Better informed individuals are prompted to make a "current request" for euthanasia at an early stage when a progressive illness is diagnosed, to make sure they can actually benefit from it. Doctors and carers, for their part, may be pressured by patients or relatives. Moreover, they may feel powerless to take into account what some patients who are experiencing unbearable suffering have clearly requested. The current situation is therefore unsatisfactory for everyone: patients, families and carers.

The Committee considers it unfair that individuals who, on account of the very pathology afflicting them and causing them suffering, are unable or no longer able to explicitly confirm their request for euthanasia, have to anticipate this situation occurring, not according to their own needs, but in order to fall within the current legal framework and not risk being excluded from it as a result of the often unpredictable progression of their illness.

Consequently, the members of the Committee unanimously recommend that the current legal framework be amended to rectify this situation, and that the public be made aware of these issues, which directly affect them.

The Committee emphasises the fact that giving individuals who so wish, within a carefully designed legal framework, a form of control over their end of life in the context of pathologies that often lead to a feeling of "loss of self" is a direct contribution to respecting and supporting individuals in what they are going through, and that this may help alleviate the anxieties that come with these situations. The Committee believes that it is a question of restoring a form of fairness between people with illness, whatever their pathology(ies). It is also a question of demonstrating that society does actually stand in solidarity with individuals suffering from illness, when these individuals have expressly communicated their wish, in a carefully considered and detailed advance directive, to receive euthanasia on account of a pathology which irreversibly affects - or would - their capacity to decide for themselves and which would render them incapable of confirming their wish in the context of a "current request" for euthanasia as provided for in the current legal system. Such an advance directive would specify

what these individuals consider, when they draw it up, to be the source of unrelievable suffering (physical, psychological, social and/or existential), which may still develop.

- *Second point of consensus: the advance directive as the relevant legal basis for the request for euthanasia, as a presumption of the patient's current wishes.*

Since the Committee believes that it must be possible to respond to the experience of individuals whose capacity to make decisions for themselves is suddenly or progressively impaired by a pathology and who therefore wish to have recourse to euthanasia according to a timetable that meets their own needs, it appears that **the advance directive is an appropriate ethical and legal vehicle to allow the person concerned:**

- **to record**, while (still) capable of doing so, their wish to receive euthanasia at a later date, in the case of an illness which irreversibly impairs, or would irreversibly impair (according to the current state of medical knowledge) their capacity to decide for themselves;
- **to explain** in detail:
 - what, in the general and specific effects of the disease (e.g. inability to recognise one's loved ones, participate in certain social activities, fundamentally orient oneself in space and time, etc.), constitutes in their eyes a threshold above which they consider that the suffering will be unbearable for them, which is why they are requesting that euthanasia be carried out even though they are no longer able to confirm their request;
 - the precise arrangements (apart from those provided for in the legal framework itself) they want to have for the implementation of euthanasia, in particular any premedication.

The directive acts as a relay and represents a **crucial testimony from the person in question**, at a time when he or she is in a position to decide for him or herself:

- of their request for euthanasia in a context (foreseeable or not) of illness affecting their capacity to decide for themselves,
- what they feel they do not want to endure as a result of the unbearable suffering from the disease,
- and their understanding of the euthanasia itself (within the framework of what the law allows).

The wish to resort to euthanasia as communicated in the advance directive does not constitute a firm and definitive commitment: the Committee would point out that, in accordance with the legal framework, any request for euthanasia can always be withdrawn, without any particular

form and at any time. Nevertheless, the advance directive, once completed and signed in accordance with the conditions laid down by law,⁹⁷ constitutes, in the Committee's view, more than just a one-off confirmation of the person's wishes; **it must take the place of a triple presumption**:

- as regards the *a priori* long-term nature of the request for euthanasia made voluntarily, after deliberation and without pressure by the signatory, as long as it is drawn up in accordance with the legal framework;
- as regards the complex suffering the patient feels will result from the sudden or gradual deterioration of their capacity to make decisions for themselves following an accident or illness: suffering they are already experiencing (in the presence of symptoms or the prospect of the illness progressing), or suffering they anticipate (future suffering) in connection with an accident or illness that would result in them being incapable of making decisions for themselves;
- as to whether the suffering is likely to be unbearable when the effects of the disease reach one or more clearly identified thresholds described in the advance directive.

In legal terms, the existence of a presumption means that what is presumed is taken to be true and no longer needs to be proven. The burden of proof is therefore reversed: the request for euthanasia is presumed to be still applicable and long-term, just as suffering is presumed to be real and unbearable when the elements that the person has described in his or her advance directive actually occur (for example, a specific threshold of impaired capacity linked to the illness).

While all members of the Committee agree on the triple presumption associated with the advance directive, which gives it a certain weight, they were unable to agree on whether this

⁹⁷ The current framework provides for the following conditions (art. 4, § 1, of the law of 28 May 2002 on euthanasia) (freely translated): "One or more trusted adults may be designated in the directive, ranked in order of preference, who will inform the attending physician of the patient's wishes. In the event of refusal, impediment, incapacity or death, each confidant replaces the person who comes before him or her in the directive. The patient's attending physician, the physician consulted and members of the care team cannot be designated as confidants.

The directive can be made at any time. It must be recorded in writing, drawn up in the presence of two adult witnesses, at least one of whom has no material interest in the declarant's death, and dated and signed by the declarant, the witnesses and, if applicable, the confidant(s).

If the person wishing to make an advance directive is physically unable to write and sign, his or her declaration may be recorded in writing by an adult of his or her choice, who must not have any material interest in the declarant's death, in the presence of two adult witnesses, at least one of whom must not have any material interest in the declarant's death. The directive must specify that the declarant cannot write and sign, and state the reasons why. The directive must be dated and signed by the person who has written it, by the witnesses and, if applicable, by the confidant(s).

A medical certificate certifying permanent physical incapacity must be attached to the directive. The directive is valid for an indefinite period". (emphasis added).

presumption should be absolute (irrebuttable) or relative (rebuttable) (see: point 3.2. Points of dissent).

- *Third point of consensus: the importance of advance care planning as a support framework for the patient and the care team*

While there is no "right to euthanasia", there is a right to request euthanasia and to have this request entertained and, where appropriate, effectuated in a care setting. The complexity of the situation discussed here has been highlighted in this opinion, in particular in the clinical vignettes.

It is therefore essential that, in the case of close medical monitoring of a progressive disease and, apart from that, in the case of general health monitoring, this advance directive is drawn up with or brought to the attention of the attending physician (specialist or GP) and discussed in the context of advance care planning. This dialogue between the patient and his or her medical team, which is based on the advance directive or makes it possible to draw it up in precise detail, is essential if the directive is to be more than just a "paper formality". That being said, the fact a dialogue takes place should not, in the Committee's view, constitute a formal procedural constraint on the validity of an advance directive. This dialogue may become impossible, for example in the event of a sudden and irreversible change in the patient's capacity to make decisions.

Euthanasia - the etymology of which ("good death") should be recalled here -in the understanding that has developed in Belgium over the last 20 years, is conceived as an act which is part of care, in the case of a serious and incurable illness or accident that causes the patient constant and unbearable suffering and puts him or her in a hopeless situation. It is a care process, which implies both a medical and a relational dimension.

The decision to implement euthanasia in the context of an advance directive in an individual who is no longer able to exercise his or her rights, while still conscious, may be made more difficult or sensitive for the physician by certain aspects of the situation and depending on whether advance care planning is possible, and the Committee recommends that the physician:

- bases his or her judgment on the opinion of two independent colleagues (psychiatrists and/or specialists in the pathology in question), in particular on whether the damage suffered is irreversible and if there is a link with what is expressed in the advance directive;
- organises a multidisciplinary consultation if a multidisciplinary team is involved in the patient's care;
- talks with the family and loved ones, provided the patient has not objected to this.

If the patient's family or loved ones are consulted, it is with a view to helping the doctor understand the patient's exact wishes and values, and not to allow the family to object to the patient's wishes or to oblige them to take responsibility for the decision. Indeed, representation is not possible when it comes to making a request for euthanasia. It is nevertheless important, to the extent possible, that this request has been discussed with those close to the patient, to allow the doctor to obtain all possible advice, organise support for the relatives and the mourning process, and limit any tensions that could surround or follow the euthanasia process.

All the members of the Committee consider that regularly reiterating the content of the advance directive is a **responsibility shared between the care staff and the person him/herself, including his/her confidant and accompanying relatives.**

It is essential that any mention of the advance directive and advance care planning is documented in the medical record, along with the minutes of consultations held with the various stakeholders.

- *Fourth point of consensus: euthanasia as a response to unbearable suffering in the context of irreversible impairment of the capacity to decide for oneself.*

If euthanasia is an act of care that reflects its etymology, it is also because it puts an end to suffering from an accident or illness that leads, among other things, to the loss of the capacity to decide for oneself, and that this suffering cannot be alleviated despite the options available in the context of care. The Committee stresses that the concept of "suffering" refers to a different, though not exclusive, dimension than that of "pain". Both have a subjective element (even the pain measurement tools used in clinical practice are based on self-assessment), and both pain and suffering are likely to result in physical and/or psychological manifestations that can be observed by others. In certain contexts, suffering can also refer to an additional, *existential dimension*, that of an individual's relationship with his or her future as a human being and with his or her own finiteness. This existential, non-pathological and ontological dimension transcends religious and philosophical divides. It is also one of the sources of spirituality (including secular spirituality) and culture in human societies.

It is not entirely possible to "dissect" what suffering means: it is an *experience* that often draws on several layers of human experience, and is perceived as a *state* in which different types of perception and consideration come together (see section 3.5.2 above).

The Committee wishes to **expressly recognise that the impairment of the capacity to make decisions for oneself due to an accident or progressive illness can, alongside physical, psychological and/or social components, generate truly existential suffering that can be difficult, if not impossible, to alleviate.** The specific feature of this existential suffering is

that it can occur very early, and "haunt" individuals by the fact it will come: the prospect of no longer being able to decide for themselves seems to some people to be utterly unbearable, as it undermines the most intimate sources of their personality and identity. In an advance directive, the aim would be to define in advance the outlines of a condition deemed unbearable when the directive is drawn up.

In a number of cases, this suffering is specific to the "*then-self*" and dissipates as the illness progresses and the "*now-self*" emerges, but it can remain intense, even intensifying, and become unbearable.

The Committee wishes to recognise human suffering in all its various forms and complexity, in terms of both its manifestations and its various dimensions, including its existential dimension.

The Committee considers that, **when the effects (actual or feared) of an illness or accident which deprives or will deprive a person of his or her capacity to decide for him or herself actually create unbearable suffering, possibly experienced in a predominantly existential way, it is legitimate to consider recourse to euthanasia after the capacity to decide for oneself has gone, provided that** a sufficiently substantiated advance directive (cf. points above) has been drawn up.

4.2. Point of dissent: advance directive as a rebuttable or irrebuttable presumption

While all members agree that the advance directive represents a triple presumption concerning (i) the validity and long-term nature of the request, (ii) the occurrence of suffering due to an accident or pathology which deprives or would deprive the person of his or her capacity to decide for him or herself, and (iii) the anticipation by the person concerned that this suffering will become unbearable once the thresholds described in the advance directive are reached or exceeded, only some members consider that this presumption cannot be rebutted (that it is, in technical terms, irrebuttable).

A) Position that the advance directive is irrebuttable

For the members who support this position, an advance euthanasia directive as described above gives individuals who so desire the possibility to detail in a carefully established framework what they consider to be unbearable suffering, which attests to the profound and *considered* nature of their approach. They also believe that, as suffering is by definition personal and at least partly subjective, no-one other than the person concerned can define what constitutes unbearable suffering. **As a result, no-one else - not even the doctor who closely monitors the person - is in a position to question *with certainty* what the person**

may have indicated in his or her advance directive; the patient him or herself can always modify or withdraw his or her advance directive as long as he or she is deemed capable of doing so. For these reasons, these members consider that the advance directive constitutes a presumption that cannot be overturned on the basis of any counter-indications (or deemed to be a counter-indication by the doctor and/or family and friends) displayed by the person once he or she has irreversibly and completely lost the capacity to decide for himself or herself on the matter. They believe that the most reliable element to relate to in a fluctuating situation, characterised by the loss of the capacity to decide for oneself is, precisely, what may have been stated *before this loss*.

Possibly delaying the implementation of the advance directive, for medical reasons or human considerations that need time for reflection and discussion, does not necessarily mean it is abandoned.

The legal recognition of the advance directive as being irrebuttable adds to its morally binding character, more so than when it is considered as an indicative document.

However, these members recognise a doctor's right to refuse to carry out euthanasia if, in his or her opinion, the legal conditions are not met, or if he or she wishes to invoke the conscience clause.

B) Position that the advance directive is rebuttable

On the other hand, other members believe that the advance directive constitutes a particularly strong presumption, but that it is not absolute due to the specific features of the situation being explored, and that it can therefore only be overturned on the strict condition that the care relationship persistently demonstrates that euthanasia is no longer the patient's wish. These members draw attention to the fact that, contrary to the current framework for the advance directive, the person who has lost the capacity to decide for him or herself *is not unconscious*. They "live their life", even if it is limited by the illness. As such, they still have experiences that may make sense to them at the time, that may bring satisfaction, pleasure or even joy, which may even be expressed. To ignore what individuals experience and express once the disease is advancing would be not only to make an *a priori* hierarchy between *then-self* and *now-self*, but also to *deny* the latter, by prioritising what has been written down at the expense of what is now experienced. Systematically applying the advance directive, without the possibility of adapting it, would mean the patient runs the risk of getting euthanasia administered despite the fact that there are clear signs the patient is adapting to the disease (as described below), putting the doctor and carers in an ethically and emotionally difficult situation.

Highlighting the complexity of this situation for doctors in the Netherlands, who are already faced with this type of decision, the Royal Dutch Medical Association (KNMG) stressed that *"the life of a person with advanced dementia is worth protecting, regardless of what the patient has previously put down in writing in this regard. The current wishes, interests and preferences of a person with advanced dementia deserve to be respected."*⁹⁸⁹⁹.

The members who support this second position believe that, **while the advance directive has a high degree of legitimacy, this should not be absolute, and that the triple presumption it implies could be overturned if contradictory, repeated and persistent signals directly from the person concerned are observed, which call into question the presumption that the request is unchanged and that there is severe suffering. They believe that it is extremely difficult to assess whether the suffering is unbearable** without an in-depth dialogue with the person themselves, which may no longer be possible depending on the type and stage of the disease¹⁰⁰. It is these contradictory signals that are interpreted, not the suffering itself.

These members are well aware that interpreting these signals is particularly complex, and feel that this should be repeated periodically, in the context of advance care planning, to take account of the evolution of the pathology and its effects which, having possibly evolved, are likely to cause major or intense suffering at a later date. If this were the case, it would then be possible to take the advance directive into consideration again.

On account of its complexity, the doctor in charge should make this interpretation, in consultation with at least two other doctors specialising in the condition/situation and/or psychiatrists.

⁹⁸ The KNMG is the Royal Dutch Medical Association. KNMG Guideline / End-of-Life Decisions, 2021. <https://www.knmg.nl/download/knmg-guideline-end-of-life-decisions>, p. 32. It should be noted that the KNMG also recommends that euthanasia should only be carried out in the presence of "actual unbearable suffering of the patient", a point that is nuanced in the Committee's position.

⁹⁹ *Contra*: the quote continues as follows: "Having said that, the previous advance directive for euthanasia could still be respected in exceptional situations. In that case, it is only considered justified if the performance of euthanasia is consistent with the previous advance directive for euthanasia and if there are no contraindications for this (for example, clear signs that the patient no longer wants euthanasia). In addition, there must be actual unbearable suffering of the patient", KNMG, *op. cit.* p. 32. The KNMG recommends adhering to a criterion of severe suffering, which can probably be clinically assessed by certain signs (refusal to eat or lack of interest in food, withdrawal and refusing to interact, despondent attitude, etc.). The Committee did not wish to adopt the wording "actual unbearable suffering" given the fact that it is impossible, explained earlier in the opinion, to objectify such suffering and confirm that it is unbearable through a hetero-assessment. In the position adopted by the Committee, suffering is presumed, as the steps to draft an advance directive have been taken, and unless strong contradictory clues are observable.

¹⁰⁰ In this context, the KNMG suggests that: "If euthanasia is not possible, the physician may, in consultation with the relatives or the patient's representative, consider the advance directive for euthanasia as an indication for withholding or withdrawing life-prolonging treatments", *ibid.* p. 33.

In addition to this medical assessment, these members recommend a broad consultation process:

- with the teams who work with the person on a daily basis, including household helpers and care assistants, who are closest to what the person is experiencing,
- with the confidant(s) designated in the advance directive and, where possible and if the person has not objected, with close family and loved ones.
- In addition, some members consider that such consultation could possibly take the form of "a priori" monitoring, evaluation or advice (to be distinguished, by their nature, from the "a posteriori" directive of euthanasia carried out as provided for in the current law)¹⁰¹. Such an evaluation could be based on a report of consultations carried out by doctors specialising in the disease, suggestions for further symptomatic control, measures taken or not taken in this respect, and their impact on the signs of suffering¹⁰².

The members defending Position B (where the advance directive is considered rebuttable) believe that, when the person, after developing the disease, shows repeated and persistent signs that are completely at odds with the presumption of serious suffering implied by the advance directive, that he or she seems - for example - not only to be adapting well to life with the disease but also to be experiencing pleasure and interest in daily life, the physician may, after taking the advice and arranging the consultations described above, consider that the **triple presumption that a voluntary, considered and unpressured request is persistent, due to suffering which is intense enough to be unbearable, has apparently not been met**, and then consider that proceeding with euthanasia under these conditions would be the same

¹⁰¹ De Lepeleire, J., Beyen, A., Burin, M., Ceulemans, L., Fabri, R., Ghijsebrechts, G., Lisaerde, J., Temmerman, B., Van den Eynden, B., & Van den Noortgate, N. (2009). Euthanasie bij personen met dementie: reflecties van artsen. *Tijdschrift voor Geneeskunde*, 65(14-15), 666-671. <https://doi.org/10.2143/TVG.65.14-15.2000584> p. 670 (freely translated): "They therefore raise the question of whether, in such situations, after multidisciplinary consultation and maximum use of existing care possibilities, a procedure could be developed with end-of-life advice based on "a priori control". Reprinted in: De Lepeleire, J., Lisaerde, J., Tobback, C., Verhaeverbeke, I., Ghijsebrechts, G., Herweyers, K., Pattyn, I., & Van den Noortgate, N. (2022). Euthanasie en dementie: reflectie op het KNMG-standpunt 'Beslissingen rond het levenseinde'. *Tijdschrift voor Geneeskunde*, 78(22), 283-287. [https://doi.org/10.47671/TVG.78.22.028\[#95](https://doi.org/10.47671/TVG.78.22.028[#95);

¹⁰² Cf. Federatie Palliatieve Zorg Vlaanderen, *Palliatieve zorg en dementie: levenseindebeslissingen. Reflectienota*, Vilvoorde (2018), p. 15-16. It is also suggested that such an *a priori* opinion could, where appropriate, be issued in conjunction with an ethics committee within the institution (hospital or nursing home), possibly in the form of an *ad hoc* consultation, as is already the case in some ethics committees, including a body not directly involved in care. Given the nature of illnesses, euthanasia in these cases is never as urgent as a current request for euthanasia from a patient who is capable of deciding for themselves, for example in the case of acute pain associated with terminal cancer. *A priori* control can also offer more legal certainty and avoid subsequent debates, without making *a posteriori* directives superfluous. See <https://palliatievezorgvlaanderen.be/wp-content/uploads/2021/06/REFLECTIENOTA-%E2%80%98PALLIATIEVE-ZORG-EN-DEMENTIE-LEVENSEINDEBESLISSINGEN.pdf>

as giving precedence in all circumstances to what a previous text says over what seems to emerge from the person's current experience of life itself.

In this second conception, the presumption is therefore rebuttable.

In this case, the legislator will have to take an explicit position on who is to make the final decision, once the above-mentioned consultations have taken place. There will be unclear, fluctuating situations, potentially generating disagreements and conflicts. Specifying the arrangements of the consultation and ultimate responsibility will protect the actors involved.

5. Conclusions and Recommendations

The underlying question in the case of an advance euthanasia directive before a person's capacity to decide for themselves is impaired, is that of **situating their autonomy**. Is autonomy fully incorporated into, and expressed by, the advance directive? Or can - or should - what the person has expressed once he or she has lost the capacity to decide for him- or herself (concerning his or her health and end of life) also be taken into account? If so, how do we link the advance directive - carefully considered, detailed, explicit - with other, more diffuse forms of human communication that are attitudes, expressions and all the verbal and non-verbal signals that can be observed phenomenologically in interactions with the person concerned?

The ethical discussions above show just how complex and problematic the subject of euthanasia is for individuals suffering from dementia or impaired decision-making capacity. That is why, despite numerous points of consensus, it has not been possible to arrive at an unequivocal position in this opinion, and why two positions have been proposed (see above). The broad range of visions is reflected in the Committee's positions. However, this does not prevent the Committee from issuing a number of conclusions and recommendations intended for legislators, Belgian institutions and citizens who, in one way or another, may feel concerned by this issue:

- 1) The Committee unanimously recommends **that the current legal framework on euthanasia be amended to broaden the scope of the advance euthanasia directive, and make it possible for euthanasia to be considered for the benefit of people who are conscious, but whose capacity to decide for themselves and express their will have been irreversibly impaired as a result of accident or illness.**
- 2) The Committee recommends that **the circumstances in which a person would want to receive euthanasia are very clearly specified in his or her advance directive, including certain arrangements regarding implementation** (in compliance with the

conditions to be laid down in the revised law). Given the complexity of drafting and interpreting an advance directive for euthanasia, it is recommended that, wherever possible, the process be accompanied by a doctor or other competent person or organisation. Given the irreversible nature of euthanasia, it is strongly recommended that the procedure include prior consultation between the doctor considering carrying out the euthanasia, the other doctors and members of the care team involved, and the patient's family.

- 3) In the context of progressive illnesses, the loss of the capacity to make decisions for oneself must be understood as a progressive phenomenon, the pace of which is partly unpredictable and specific to each individual afflicted. This capacity can therefore fluctuate over a fairly long period. As long as the capacity to decide for oneself is not irreversibly impaired, it remains possible for the individuals concerned to request euthanasia on the basis of a so-called "current" request. **The assessment of decision-making capacity (the patient's ability to make a medical decision, in particular regarding euthanasia) is the responsibility of the physician, in collaboration with the multi-professional team** if such a team is involved with the patient. There is no perfect tool for objectifying decision-making capacity, which is different from cognitive ability, and is at least partly contextual and specific to the type of decision to be made. **We should recall that autonomy is not only linked to cognitive abilities, but is also a function of relationships and the support these relationships provide to capacities that may be faltering.** As such, before declaring that the person is no longer capable of making a "current request" for euthanasia, it is advisable to ascertain with prudence and caution his or her capacity to decide for him or herself on the matter.
- 4) The Committee recommends **recognising the complex nature of the suffering caused by the loss of the capacity to make decisions for oneself**: if suffering is in essence an experience that goes beyond a "simple" combination of physical and/or psychological symptoms to constitute an *experience*, it seems appropriate to take into account the possible *existential dimension*, which can be perceived as soon as a progressive illness such as dementia is diagnosed: **it is not just a question of a current or feared loss of potential and abilities, but also of what, for many people, forms the basis of a more or less stable sense of being and identity.** Of course, the vagaries of life (bereavement, serious illness, etc.) almost always call into question the identity we have forged for ourselves, and often lead us to rework it. However, the impairments discussed in this opinion can sometimes result in actual or anticipated suffering, due to the prospect of "losing oneself". This specific loss - and the fear it can induce - are likely to lead to severe suffering, possibly perceived as unbearable by some, which the Committee wishes to recognise.

5) For this reason, the Committee recommends that the advance directive be considered as a **triple presumption**:

1. of the **long-term** nature of the request for euthanasia made voluntarily, after deliberation and without pressure by the signatory, as long as it is drawn up in accordance with the legal framework;
2. of the **complex suffering** the signatory believes results from the sudden or progressive loss of their ability to make decisions for themselves following an accident or illness;
3. of the **anticipated unbearable suffering**, once the effects of the illness reach one or more thresholds clearly identified and described by the person concerned in their advance directive.

Whether or not this triple presumption can be rebutted is not, however, the subject of consensus within the Committee, and will have to be decided by the legislator.

6) The Committee considers that **advance care planning, introduced in 2024 in the law of 22 August 2002 on patients' rights, is an appropriate and relevant tool for starting dialogue around the advance directive, and that this dialogue is the shared responsibility of carers, on the one hand, and the patient (possibly supported by his or her confidant and/or family), on the other.** It is not desirable for the advance directive to be a document that is drawn up one day and then forgotten: in the case of an evolving situation in particular, it is important to reiterate the dialogue and elicit the patient's wishes at stages of the illness when they still have sufficient capacity to express themselves. It is also recommended, wherever possible, that this dialogue be led by the same individuals on the care team, so that this continuity supports the autonomy of the patient with potentially fluctuating cognitive difficulties, and that a shared understanding is also built up within the care team. **Sessions of this dialogue will be recorded in the patient's file.** The Committee reiterates that an advance directive for euthanasia does not constitute an absolute guarantee that the person's wishes, as understood by that person, will be carried out. On the other hand, it establishes a framework that (i) gives fundamental weight to the expression of will that the person has laid down in his or her directive, and (ii) invites dialogue and shared reflection in a complex and sensitive context.

While the Committee strongly recommends reiterating this discussion within the planning process in the event of an evolving pathology, **it does not recommend making it a formal procedural condition which, if not respected, would render the advance directive inapplicable**, in order to avoid penalising patients whose situation suddenly worsens before they have had a chance to see their doctor again. Finally, the

presence of witnesses during the drafting of the advance directive could help verify its authenticity if it is drafted outside a planning process, or even in the absence of any physician or healthcare professional who could attest to the fact that the matter was discussed in the patient file.

7) Regardless of the legislator's choice as to the scope (relative or absolute) of the presumption established by the advance directive, the Committee recommends that **before any implementation of the advance directive, it be carefully weighed and discussed, at the least:**

- **with two doctors specialising in the pathology/situation and/or psychiatrists**, whose role would be to confirm the damage caused by the illness, including the irreversible loss of the patient's capacity to decide for him or herself regarding euthanasia (and therefore the relevance of taking into account the advance directive and the weight to be given to it). It would also be up to the latter, where appropriate, to make suggestions for relieving the pain or improving comfort;
- **in the context of a consultation with the person(s) who accompany(ies) the patient on a daily basis (care teams);**
- **in the context of a consultation with the confidant(s) designated in the advance directive** and, unless the patient has objected, with some or all of his or her other relatives.

These different stages of advice and consultation should make it possible to protect:

- the patient, as a person made vulnerable by his or her illness or health situation;
- the carers, in particular the doctors involved, to ensure their freedom of conscience and protect them to the extent possible from any pressure - in particular if they are not convinced that they are relieving suffering or responding to the patient's wishes.

In the event that the legislator deems that the presumption established by the advance directive is rebuttable (and can therefore be reversed), they should also make it possible to analyse and discuss the presence and interpretation of any contradictory, repeated and persistent signs that would negate the presumption of unbearable or major suffering on the part of the patient and/or his or her wish to receive euthanasia.

A control, evaluation or support prior to the decision by a body outside the situation could also be envisaged - a possibility on which there is no consensus within the Committee.

8) The Committee recommends that **public campaigns be conducted, in order to:**

- **inform citizens about this new system and the general framework for euthanasia** through appropriate awareness-raising campaigns, aimed at improving awareness of the legislation (current and possibly future) among the general public, as well as of systems and initiatives relating to end-of-life, advance directives and advance care planning, so that the public has a realistic view of what is possible and what is not, and of the steps to be taken to possibly receive euthanasia at a later stage; and
- at the same time, **help deconstruct prejudices regarding dementia and the loss of independence and the capacity to make decisions for oneself**. These prejudices lead to an overly negative image not only of the disease, but also of the people suffering from it. It should be reiterated that the relationship with the person must be continued, and their autonomy supported, through contacts, whether verbal, visual or other, and that care needs must be met (see also the final recommendation on palliative care). In this respect, when communicating with the general public, it is advisable to propose alternative visions to the prevailing societal view of dementia or cognitive impairment (reframing). The current social representation has a strong influence on the quality of life of sufferers and their families. The negative way they are seen by the rest of society becomes part of their problem. For now, it is a "loss model", with all the consequences that entails. One of the challenges of this reframing is to bring back the human aspect in the face of illness, and enable patients to participate in social life for longer.

9) **If individuals with dementia or another condition want to revise their advance directive, they must be able to do so at any time** as long as they are still capable of making their own decisions in this regard. A person's prior wish, expressed when they were still autonomous and competent, takes on more moral authority as their ability to perceive new critical interests and experiential interests (pleasures) diminishes¹⁰³. If the legislator were to consider that the presumption must be irrebuttable and that the advance directive must, as a matter of principle, be implemented, it would then be up to the patient to describe in the advance directive the circumstances which, in his or her opinion, would constitute a withdrawal of the advance directive (for example, certain behaviour that suggests the patient refuses euthanasia). Indeed, from this perspective, only the patient can decide that the directive must no longer be applied and must be withdrawn.

¹⁰³ Paul T. Menzel and Bonnie Steinbock, "Advance Directives, Dementia, and Physician-Assisted Death," *Journal of Law, Medicine & Ethics*, summer 2013.

10) The principle of prudence/precaution requires that euthanasia on the basis of an advance directive should not be carried out in the event of a sudden incident, such as a recent stroke or the onset of acute confusion in a person suffering from dementia. Acute episodes may be followed by an improvement in the person's condition, and are therefore not a good starting point for comparing the situation with the description of his or her wishes that were written in advance. The decision to carry out euthanasia must always be the conclusion of a process, of support in a situation that is evolving and generating irreversible damage.

The necessary conviction on the part of the care team to act in the patient's best interests by ending his or her life through euthanasia can only be achieved in a context of optimal care and services. Even if it is essential to accept a margin of uncertainty, in particular in situations made complex by the patient's incapacity to express their wishes, this margin can be reduced by the ongoing dialogue already mentioned, and by the fact that the person is receiving the care that will enable him or her to continue to find comfort and meaning in life. As was the case in opinion no. 84¹⁰⁴, the Committee is referring here to the importance of **palliative care**. This importance implies **the need for all those involved to be trained in palliative care, dementia care, advance care planning, receiving a request for euthanasia, etc., as well as various institutional, political, organisational, communication and financial conditions to ensure that such care can actually be implemented. In particular, the system for financing palliative care and advance care planning should be designed to ensure that all citizens have access to this care, whatever their socio-economic level, the nature of their pathology and the setting in which they may be treated**¹⁰⁵. Some individuals will be better equipped than others to benefit from a prior doctor-patient dialogue, so that they can draw up a clear and precise advance directive, and therefore assert their self-determination.

The Committee also supports developing a policy for living with cognitive impairment in nursing homes, including the pharmacological and non-pharmacological measures recommended to limit the symptoms associated with the disease, and adopting a person-centred approach focused on preserving dignity, autonomy and social ties.

¹⁰⁴ Opinion no. 84 of 27 March 2023 concerning the availability of medical care, in particular comfort and palliative care, in nursing homes in the context of the COVID-19 pandemic. <https://www.belgiumnationalbioethicscommittee.be/documents/dPvbBTGxRBmludXM2I57Wgo15>

¹⁰⁵ See recommendations formulated by the Federal Cell for the Evaluation of Palliative Care (French only). <https://organesdeconcertation.sante.belgique.be/fr/documents/2020-rapport-devaluation-des-soins-palliatifs>

Finally, the Committee underlines the possible suffering caused by these situations to family members and healthcare professionals. It would be advisable to create a **space to support** each other.

Note on the use of artificial intelligence in the Committee's work

Artificial intelligence (AI) is never used to lead or guide the ethical reflections of the Belgian Advisory Committee on Bioethics, nor is it used to draft the final text of the opinions it issues. These are exclusively the fruit of in-depth discussions, hearings and deliberations between members of the Committee, meeting in restricted commissions and plenary sessions. Ethical reasoning, its foundations and conclusions are entirely a matter of human expertise. This is a fundamental principle from which the Committee does not depart.

In any event, full responsibility for the content, coherence and ethical validity of our opinions is with the members of the Committee, who have sole competence to approve them.

Transparency and Pluralism Clause of the Committee

The Belgian Advisory Committee on Bioethics is an independent and pluralistic body that upholds linguistic and gender balance. All members are required to submit a declaration of interests at the start of their mandate and update it whenever necessary.

In keeping with the pluralistic nature of ethics committees, the composition of the Committee is carefully structured to ensure balanced representation of the various philosophical currents present in society, alongside linguistic and gender equity. Members are not expected to conceal their convictions or affiliations, provided these are expressed in a personal capacity and in a manner consistent with the Committee's mission and the spirit of dialogue that must guide its deliberations.

This opinion began was prepared in the select committee “Euthanasia”, consisting of:

Joint chairpersons	Joint reporters	Members	Member of the Bureau
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Virginie Pirard	Martin Hiele	Patrick Cras	Virginie Pirard
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		Franck Devaux	
		Christel De Pooter	
		Willem Distelmans	
		Chris Gastmans	
		Gilles Genicot	
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		Vincent Seutin	
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This opinion can be accessed at www.belgiumnationalbioethicscommittee.be.