Reflection paper

Committee for a more dignified death

1. Introduction

1.1 Terms of reference

On 14 September 2023, the government announced that it would set up the Committee for a more dignified death.

According to the Committee's terms of reference, the Committee's task was,[1] among other things, *to "include the legal and health consequences of possible initiatives in continuation of existing practice for the care and treatment of palliative patients*" and to "*create a debate with ethical considerations about the way Danes perceive dignity in the last phase of life.*"

The Committee's discussions were to result in a reflection paper that would "*embrace Danes' views on both natural death and assisted end of life with a view to including Danes' views in the reflection paper.*" Thus, the Committee's work would "*help nuance the government's decision-making basis for a Danish model for a more dignified death*".

1.2 The Committee

The Committee has gathered seven times in twelve months, and it was clear from the first meeting that virtually all of the most prominent views on a dignified death are represented in the Committee with the exception of supporters of what the Danish Council on Ethics calls "the Dutch model" in "Opinion on assisted death (2023[2])". The Committee has had speakers from the Danish Council on Ethics, the Danish Health Authority and the Danish Patient Safety Authority.

1.3 Content

The reflection paper contains the following:

- Majority reflections and proposals (Kathrine Lilleør, Camilla Thorn Kristensen, Janne Rothmar Herrmann, Janus Tarp, Kim Oskar Bakbo-Carlsen, Kirsten Jacobsen, Lars Lior Ramsgaard, Thomas Søbirk Petersen)
- Minority reflections and proposals (Janus Tarp)
- The Committee's joint reflections and proposals
- List of definitions
- List of references
- Appendix 1: The Committee's terms of reference
- Appendix 2: Committee members
- Appendix 3: Debate and enquiries received (published separately)

As the terms of reference instructed the Committee to inspire public debate, expressed as "*the purpose of the Committee is to initiate a dialogue with Danes about a more dignified death*", the Committee adopted two innovative initiatives.

One initiative was to set up an email under the auspices of the Ministry of the Interior and Health of Denmark where people would be able to post their input, experiences and perspectives on the topic. The mailbox was open from 13 June 2024 to 1 October 2024.

The Committee has received 92 enquiries from citizens and organisations in the mailbox. As a starting point, the Committee has included all enquiries in Appendix 3. Only enquiries that may seem grossly offensive or in violation of copyright rules in the opinion of the Secretariat have been excluded. The Committee then decided that all contributions would be included unedited and in anonymised form as

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[1] The Ministry of the Interior and Health of Denmark (2023). Terms of reference for the Committee for a more dignified death.

[2] The Danish Council on Ethics (2023). Opinion on assisted death from the Danish Council on Ethics.

appendices to this reflection paper. For printing purposes, Appendix 3 is published as a separate part of the reflection paper.

The second initiative was that half-way through the Committee's work at Folkemødet 2024, the Committee would announce the positions it had reached at that time in order to inspire debate and listen to feedback. This helped intensify and qualify the debate, and the topic has been increasingly discussed in public with a view to "*a Danish model for a more dignified death*", which can be "*an extension of existing practice for the care and treatment of palliative patients*". In addition, the members have, together and individually, participated in numerous debate events across the country and have expressed their opinion in the public debate in general.

1.4 The debate

From the Committee's first meetings, it was clear that the Committee's views were generally divided into a majority and a minority. The majority were concerned with improving palliative care and discussing new initiatives centred on autonomy as an extension of current practice. The minority, on the other hand, only saw a need to strengthen the current palliative tradition and practice.

Two of the Committee's ten members resigned from the Committee on 21 May 2024. However, the opinions expressed by those two members in the Committee work are included in this reflection paper under the minority's reflections and proposals.

The two resignations combined with the public debate and discussions at meetings have shaped the Committee's reflections. The topic of finding ways to ensure that individuals can expect a dignified death evokes many emotions. The majority of the Committee has therefore chosen to recommend measures that, in the opinion of the majority, are close to current practice for the treatment and care of palliative patients, giving voice to those who do not consider current practice sufficient.

However, the entire Committee agrees that before moving forward with new initiatives and a possible new "*Danish model*", palliative care must be strengthened in line with the Danish Health Authority's 2017 recommendations[3]. Anyone with palliative needs and wishes should be able to receive basic and specialised palliative care regardless of where they live in Denmark.

1.5 Summary of the Committee's proposals

Majority proposal: 7 out of a total of 8 Committee members (the majority) believe that self-chosen and self-executed end of life should be introduced for terminal persons. 5 of those 7 members also believe that it should be possible to get assistance with executing the actual end of life (see page 10).

Minority proposal: 1 out of 8 Committee members (the minority) argues that existing options for relief and self-determination can be better utilised and that palliative care should be improved. Reference is made to a number of initiatives from the Danish Society for Palliative Medicine's 2024 strategy. Furthermore, two initiatives are recommended: the introduction of patient rights within the palliative field and the strengthening of palliative training. The minority rejects the possibility of assisted death (see pages 16-19).

The entire Committee also agrees that palliative care must be improved and agrees with the Danish Health Authority's 2017 recommendations for palliative care. In addition, the Committee proposes four initiatives: a new power of attorney system, strengthening palliative training, reintroducing palliative care kits and using non-pharmacological relief and care (see pages 20-24).

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[3] The Danish Health Authority (2017). Recommendations for palliative care.

2. Majority reflections

Self-chosen end of life for terminal persons

2.1 Two key arguments for legalising self-chosen end of life[4]

The following provides a presentation and critical discussion of two key arguments for legalisation. Next, a brief presentation of two more arguments in favour of legalisation is provided. This is followed by a critical discussion of common objections to the legalisation of self-chosen end of life. The section is concluded with a presentation of two arguments in favour of a terminal person executing their own end of life (Appendix 1) and two arguments in favour of a healthcare professional executing the end of life (Appendix 2).

2.1.1 Respect for individual autonomy

"I believe that you should have the right to choose to end your life when it's this bad. I've suffered enough. I would like to sleep in peacefully – and I would like to receive assistance in doing so. Without any fuss."

- Winnie, terminal cancer patient[5]

As Winnie says in the quote above, legalising self-chosen end of life for terminal persons can increase their possibility to make decisions regarding their own body, life (and death). In other words, legalisation will support and respect people's autonomy.[6] Respecting the autonomy of a competent person is a core value in Danish society. For example, staff in the Danish healthcare system must respect if a competent pregnant woman wants an abortion or if a patient refuses food or fluids. The healthcare system also respects wishes not to be resuscitated or wishes to opt out of palliative care. In these situations, staff must accept a competent person's autonomous decisions, even if it shortens that person's (or foetus') life.

Healthcare professionals will, of course, help with information and counselling, but the basic ethical value is that people's autonomy must be respected as long as it does not harm others. The majority of the Committee believes that it is not up to doctors or others to decide what should happen at important stages of our lives. The choice is ours. As a general rule, a competent person is the best judge of what is good for that person. The majority of the Committee does not believe that it is for others to decide when or how we leave this world if we have only a few days, weeks or months left to live and do not find the process of dying attractive or dignified. According to a number of studies, this opinion is shared by the majority of dying people who would like the option to receive assistance in self-chosen end of life.[7]

2.1.1.1.1 Objection to the autonomy argument

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[4] When the majority of the Committee uses the phrase "legalisation of self-chosen end of life", we are aware that under current legislation, it is not a criminal offence to attempt to take your own life, but it is a criminal offence under section 240 of the Danish Penal Code (straffeloven) to assist someone in taking their own life, and it is a criminal offence under section 239 to kill on request.

[5] Nielsen, A.K.B. (2022). 52-year-old Winnie is dying: I've suffered enough. Journal of Health Policy. 19 December.

[6] Young, R. (2024). Voluntary Euthanasia. In Zalta, E.N. (ed.) The Stanford Encyclopedia of Philosophy (winter 2024).

[7] See for example Chapple, A., Ziebland, S., McPherson, A., & Herxheimer, A. (2006). What people close to death say about euthanasia and assisted suicide: a qualitative study. *Journal of Medical Ethics*, 32(12): 706-710; Suarez-Almazor, M. E., Newman, C., Hanson, J., & Bruera, E. (2002). Attitudes of terminally ill cancer patients about euthanasia and assisted suicide: predominance of psychosocial determinants and beliefs over symptom distress and subsequent survival. *Journal of Clinical Oncology,* 20(8): 2134-2141, and Hizo-Abes, P., Siegel, L., & Schreier, G. (2018). Exploring attitudes toward physician-assisted death in patients with life-limiting illnesses with varying experiences of palliative care: a pilot study. *BMC Palliative Care*, 17: 1-10.

As an objection to the autonomy argument, it has been argued that dying people are often not considered autonomous individuals as they live in a desperate, agonised and hopeless state.[8] However, obvious problems are associated with this objection.[9]

Of course, dying people may be in a desperate and agonised state that makes them unfit to make competent decisions, but that is not the case for all dying people. Even patients in agony may experience periods during which they are capable decision makers. It has not been possible to find studies that provide empirical evidence that all terminal persons constantly experience a level of desperation and hopelessness that prevents them from making competent choices. On the contrary, research suggests that some dying people have, and is capable of expressing, a number of rational wishes for how to live their final days.[10] In such cases, we should respect autonomous and terminal persons' wishes for self-chosen end of life.
A problematic consequence of this objection is that in that case, we should not respect people who do not want life-prolonging treatment on their deathbed either as these people may also be in a desperate and hopeless state and therefore lack autonomy. Hardly anyone would defend that point of view.

Another concern regarding legalisation is that it will lead to pressure (from others or oneself) for dying people to choose self-chosen end of life. It is important to emphasise that the majority of the Committee sees self-chosen end of life as a right that the dying person can bring into play on their own. We believe that it should be illegal to offer or ask the person if they would choose to end their life. The wish must come from the dying person themselves. In addition, it should be emphasised that society already handles and accepts this potential pressure in relation to, for example, choosing abortion or opting out of life-prolonging treatment, and the majority of the Committee therefore believes that the same will apply in relation to self-chosen end of life. Legalisation would mean that those who want self-chosen end of life can have it, and those who do not want it can choose not to request it. Current law makes it possible to accommodate persons who do not wish self-chosen end of life only while those who want this help are not favoured because it is illegal.

2.1.2 Reducing physical and mental suffering

"I think you live up to the Hippocratic Oath if you help a severely distressed patient to die when that person is terminally and incurably ill and can't manage anymore. Deliverance for a person who wants peace. I believe that the fact alone that it will be an option for terminally ill persons will provide security and peace of mind."

- Joachim Frederiksen, consultant anaesthetist [11]

The majority of the Committee believes that legalising self-chosen end of life for terminal persons can help reduce suffering.[12] If a terminal person is in unbearable pain that is very difficult or impossible to relieve, and if the person has a desire to leave this world, self-chosen end of life can bring peace of mind

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[8] See for example Hartling, O. (2021). *Euthanasia and the ethics of a doctors's decisions*. Bloomsbury.

[9] Petersen, T.S. & Dige, M. (2023). Critique of autonomy-based arguments against legalising assisted dying. *Bioethics*, 37: 165-170.

[10] See for example Houska, A. & Loučka, M. (2019). Patients' autonomy at the end of life: a critical review. *Journal of pain and symptom management*, 57(4): 835-845, and Winzelberg, G.S., Hanson, L.C. & Tulsky, J.A. (2005). Beyond autonomy: diversifying-end-of-life decision-making approaches to serve patients and families. *Journal of the American Geriatrics Society*, 53(6): 1046-1050.

[11] Interview by Joachim Frederiksen – told to Bodil Jessen (2023) Help in the most difficult time – when life is drawing to a close (Hjælp i den sværeste tid – når livet rinder ud). *Danish Medical Journal*, 13 October.

[12] For example, one study shows that approximately 34% of individuals who want self-chosen end of life (in accordance with the majority's Appendix 1) want help because they are in pain or are afraid to end up being in pain (Oregon Death with Dignity Act. 2023 Data Summary, 14).

to the dying person. Suffering or pain is not only physical but also psychological as not being able to perform even the most basic bodily functions can be associated with great anxiety, including the loss of dignity.

2.1.2.1 Objection to the suffering argument

As an objection to the suffering argument, i.a., The Danish Council on Ethics argues that if palliative care is fully developed and functioning satisfactorily in Denmark, a framework can be created where suffering can be managed in ways that dying people will find dignified.[13] In other words, self-chosen end of life would therefore be unnecessary.

But even the best palliative care cannot make all suffering bearable. For example, patients react differently to morphine and may therefore experience severe pain, even when morphine is used in an attempt to relieve pain.[14] Bone cancer in particular can cause intense and unpredictable pain that can be very difficult and sometimes impossible to relieve effectively.[15] Another example is terminal COPD patients who may experience very intense choking sensations. It is also important to note that studies of the Death with Dignity Act from the US state of Oregon show that even among patients who received comprehensive palliative care (because they were in hospice care), several chose to receive assistance to self-chosen end of life. [16]

Of the 367 patients who chose self-chosen end of life in Oregon in 2023, 87% were in hospice care.[17] Even in states with good palliative care, there are still terminal persons who want to decide for themselves when to leave this world. There are also a number of side effects that may be difficult to avoid in palliative care, such as nausea, loss of consciousness, severe breathing difficulties, fear of choking and loss of dignity.

Referring to the autonomy argument, there are also people who do not want extensive palliative care (e.g. palliative sedation) and feel that they are forced to be dependent on others when self-chosen end of life is not available[18]. Studies of the Oregon Model show that approximately 34% cite lack of pain control as one of several reasons for choosing self-chosen end of life while approximately 90% state that they choose assisted dying due to loss of autonomy. They can no longer do the things that give them quality of life.[19] Believing that suffering and existential anxiety can be fixed with medical intervention is an illusion, especially when people do not want this intervention, although offered with the best of intentions.

To conclude our discussion of the suffering argument, some may wonder why the majority of the Committee did not include suffering as one of the necessary conditions for allowing self-chosen end of life for the dying, see *chapter 3. Majority proposal*. However, the majority of the Committee does not

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[13] The Danish Council on Ethics (2023). Opinion on assisted death from the Danish Council on Ethics.

[14] Krikorian, A., Limonero, J.T. & Maté, J. (2012). Suffering and distress at the end-of-life. *Psycho-Oncology*, 21(8): 799-808.

[15] Mantyh, P.W. (2014*)*. Bone cancer pain: from mechanism to therapy. *Current opinion in supportive and palliative care*, 8(2): 83.

[16] Oregon Death with Dignity Act. 2023 Data Summary.

[17] Ibid, 8.

[18] Ganzini, L., Goy, E. and Dobscha, S. (2009) Oregonians' Reasons for Requesting Physician Aid in Dying. Archives of Internal Medicine, 169(5): 489–492. And: Onwuteaka-Philipsen, B., Brinkman-Stoppelenburg, A., Penning, C., Jong-Krul, G., van Delden, J and van der Heide, A. (2012). Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990–2010: A repeated cross-sectional survey. *The Lancet*, 380: 908–915.

[19] Op.cit. Oregon Death with Dignity Act.

believe that suffering should be a necessary condition as studies from, e.g., Oregon show that the primary reason that dying people choose assistance to end their life is that they find their process of dying undignified.[20] However, lack of pain control plays a role for approximately 34% of people who receive assistance to leave this world. Furthermore, the majority of the Committee believes that a suffering requirement is unnecessary as dying people who find that 'enough is enough' also express a form of suffering. Choosing self-chosen end of life is also a way to express that your life, according to your own beliefs, has no more quality but consists of suffering only.

2.2 Other arguments for legalisation

The majority of the Committee is aware that there are additional arguments in favour of legalising self-chosen end of life. For example, legalising self-chosen end of life can help prevent suicides (and assisted suicides) that often end up being very violent and disastrous, especially among competent, terminal cancer patients[21]. Furthermore, there is data to support that legalisation can provide peace of mind and reassurance for people who have come to terms with their situation and for ill persons and want to make their own decisions about their life and death.[22] However, the majority believes that the two aforementioned arguments are sufficient to justify legalisation.

Arguments against legalisation

In addition to the objections to the two arguments for legalisation discussed above, the majority of the Committee would like to briefly discuss some of the other objections to legalisation that have been raised in the debate. In the following, the majority will comment on five objections.

2.2.1 First objection

The Danish Council on Ethics' latest statement on the subject states that legalising;

"*...assisted death risks leading to unacceptable changes to fundamental norms of society, healthcare and views of human nature. The very existence of assisted death will fundamentally change the way we think about old age, death, quality of life and what it means to show consideration for others.*" [23]

The majority of the Committee does not share the concern that legalising self-chosen end of life would lead to unacceptable changes in our fundamental norms. On the contrary. A liberal democracy like the one in Denmark is characterised by protecting fundamental norms such as not harming others, protecting vulnerable people and respecting individual autonomy and freedom. For example, a fundamental norm in healthcare is to respect individuals' right to informed consent and for healthcare professionals to do what they can to help people live better lives. These norms support the legalisation of self-chosen end of life. The majority has not been able to find evidence that in countries and states that have legalised self-chosen end of life (e.g. Australia, Canada, California, New Zealand, the Netherlands, Belgium, Austria, Spain and Switzerland), there have been "...unacceptable changes to fundamental norms...".

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[20] Oregon Death with Dignity Act. 2023 Data Summary: 14.

[21] Cheung, G., Douwes, G. & Sundram, F. (2017). Late-life suicide in terminal cancer: A rational act or underdiagnosed depression? *Journal of pain and symptom management*, 54(6): 835-842.

[22] BMA (2024). Key arguments used in the debate on physician-assisted dying.

[23] The Danish Council on Ethics (2023). The Danish Council on Ethics' statement on assisted death: 7.

2.2.2 Second objection

"The only thing that would be able to protect the lives and dignity of the most vulnerable persons in society will be an absolute ban."[24]

According to the majority of the Committee, there is no evidence to suggest that healthcare professionals would not be able to show consideration for the most vulnerable in society if self-chosen end of life were to be legalised. Does the Danish Council on Ethics believe that healthcare professionals in all countries and states where self-chosen end of life is legal have lost the ability to protect and honour the lives of vulnerable people? Answering yes to this question would not be substantiated. *Section 2.1.1 Respect for individual autonomy* showed that the group of particularly vulnerable people also includes competent people who genuinely want assistance with self-chosen end of life. This is the group of people that the majority of the Committee wants to help and protect with legalisation.

2.2.3 Third objection

"If we offer assisted death, we are saying, directly or indirectly, that some lives are not worth living."[25]

In relation to this concern, it is important to note that Denmark has already accepted actions in the healthcare system that end lives without claiming that authorities or healthcare professionals are sending a signal that some lives are not worth living. For example, if we are very ill, we can opt out of a treatment even if doing so will shorten our lives. Or we can have an abortion based on a prenatal diagnosis if there is a high probability that the foetus has a serious disease. These actions are fully compatible with believing that people who are sick can have good lives. The signal sent by legalising self-chosen end of life is not that some lives are not worth living. Instead, the signal is that you respect people's perspective on their own lives. The signal is that in some situations, people who are dying and suffering may have good reason to believe that their own life is not worth continuing. Respecting this perspective is something that is already recognised when people forgo palliative care, for example, or refrain from eating and drinking to shorten their life near the end.

2.2.4 Fourth objection - expanding the indication area

"Legalising euthanasia is very likely to evolve into accepting euthanasia without the patient's explicit request in certain cases."[26]

Obviously, keeping an eye out for any misuse of self-chosen end of life is important as is making sure that it is only used within the framework described in *chapter 3. Majority proposal*. But the Danish Council on Ethics's argument can be challenged in several ways. After all, we can prevent or minimise misuse by having clear descriptions of the conditions under which we will legalise self-chosen end of life. The fact that we are able to contain the use of self-chosen end of life in situations where we want to do so is very likely for the simple reason that we have managed to contain the use of end-of-life practices that are already used in healthcare today. The fact that we have had laws in place for many years allowing opting out of and stopping treatment (even if it will shorten life) suggests that misuse of this type of assisted death is very low. There also seems to be a lot of support for these laws since, as far as we know, no politician wants these end-of-life practices to become illegal. If the Danish healthcare system has been so good at preventing misuse of these forms of assisted death, it is hard to see why the healthcare system would not also be able - through legislation and education - to contain potential misuse of self-chosen end of life if legalised. Add to this that we emphasise in *chapter 3. Majority proposal* that the prescription of medication for self-chosen end of life must be registered and reported

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[24] The Danish Council on Ethics (2023). The Danish Council on Ethics' statement on assisted death: 7.

[25] The Danish Council on Ethics (2023). The Danish Council on Ethics' statement on assisted death: 8.

[26] The Danish Council on Ethics (2023). The Danish Council on Ethics' statement on assisted death: 25.

to the authorities (e.g. The Danish Health Authority and the Danish Patient Safety Authority) to ensure monitoring of the practice. Such monitoring and registration will make this practice less vulnerable to error and misuse than the end-of-life practices that most people currently accept and that are legal.

Furthermore, it is worth noting that if there had been obvious misuse in the first countries to introduce self-chosen end of life, such as the Netherlands, Belgium and Switzerland, a number of countries such as Australia, Columbia, Canada, New Zealand, Spain, Germany, Luxembourg and large parts of the US (for example California, Washington, Oregon, New Mexico and Colorado) would probably not have legalised some form of self-chosen end of life. Countries where self-chosen end of life is legal have more control over this practice (which must be reported to a special board) than over other life-shortening practices such as the lack of treatment.[27] [28] It is also worth emphasising that in the vast majority of states and countries where self-chosen end of life for dying persons is legal, there has been virtually no expansion of the indication area[29.] Since, e.g., Oregon introduced self-chosen end of life for the dying (via self medication) in 1998, there have been two changes. From 2020, it has been possible to get an exemption from the rule that 15 days must pass from the first request for access to medication for self-chosen end-of-life to the necessary second request if it is estimated that the patient will die within 15 days. In 2023, assistance was also available to non-residents of Oregon.[30] Finally, if there had been misuse in countries with self-chosen end of life, it is strange that studies show that a majority of healthcare professionals in, e.g., the UK (80%)[31] and that approximately half of doctors in Sweden (47%)[32] are in favour of self-chosen end of life for the dying.

2.2.5 Fifth objection

The previous argument belongs to a group of objections stating that if we accept self-chosen end of life for the dying, we have taken the first step towards a slippery slope that will automatically, or with high probability, lead to a morally catastrophic scenario. But what exactly this scenario is about may vary. In addition to the scenario mentioned by the Danish Council on Ethics in the previous section stating that legalisation will lead to people being killed against their will, it has been mentioned that legalisation will lead to more and more people using it and that this is a sign of a problematic slippery slope.[33] It is true that more and more people are choosing to make use of self-chosen end of life in countries where it is legal. But the fact that the number of people wanting assistance to leave this world is increasing does not necessarily show that there is a slippery slope towards something that is morally wrong.[34] Perhaps there has been a great unmet need, perhaps self-chosen end of life have been destigmatised. It is also a problematic mindset to think that more people using end-of-life practices makes it morally wrong. It will mean that if access to palliative treatment improves, more people will die in connection with palliative

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[27] Den Hartog, G. (2023) *What Kind of Death: The Ethics of Determining One's Own Death*, Routledge.

[28] In Denmark, record-keeping is required if a patient chooses to refuse treatment or discontinue treatment already initiated. It must also be recorded what information the patient has received, including information about the consequences of not receiving treatment.

[29] One exception is Canada where the indication area was expanded in 2021 so that it is no longer necessary to be dying to get access to self-chosen end of life. Wanting it, being competent, well-informed and experiencing unbearable suffering are enough. Frolic, A., & Oliphant, A. (2022). Introducing medical assistance in dying in Canada: Lessons on pragmatic ethics and the implementation of a morally contested practice. HEC Forum, 34(4): 307-319. Dordrecht: Springer Netherlands.

[30] Op.cit. Oregon Death with Dignity Act.

[31] Ibbetson, Conner. (2020). Do people in the UK support euthanasia? YouGov. 21 January.

[32] Lynøe, N., Lindblad, A., Engström, I., Sandlund, M. and Juth, N. (2021). Trends in Swedish physicians' attitudes towards physician-assisted suicide: a cross-sectional study. *BMC Med Ethics*, 22: 86.

[33] The Danish Council on Ethics (2023). The Danish Council on Ethics' statement on assisted death: 68.

[34] The Danish Council on Ethics (2023). The Danish Council on Ethics' statement on assisted death: 68.

treatment, including palliative sedation. Would this also be a slippery slope that has ended in a moral disaster? Hardly. It will only mean that more people have received assistance to leave this world the way they want.

2.2.6 Two arguments stating that only terminal persons may end their own lives

1. No doctors or nurses will be directly involved in the end of a terminal person's life.
2. The fact that the terminal person must take the end-of-life medication themselves makes it very clear that it is the person's own wish.

2.2.7 Two arguments stating that terminal persons may choose to have the end-of-life medication administered by a doctor/nurse/relative

1. This allows terminal people to live longer. There may be terminal people who want to live after no longer having the strength to perform the end-of-life act themselves. This option will increase the person's self-determination.
2. There may be terminal people who do not feel comfortable managing the end of life themselves – anxiety about doing something wrong, vomiting etc.

Objections may be that there are not enough doctors/nurses willing to execute assistance, that it will create distrust of healthcare professionals or that it is contrary to the Hippocratic Oath. However, all countries that have some form of self-chosen end of life have enough healthcare professionals who are willing to help,[35] and a high level of trust in doctors has been measured in countries where self-chosen end of life is legal.[36]

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[35] This also applies to a number of countries where self-chosen end of life is not legal. According to surveys, approximately 47% of Swedish doctors are in favour of legalising some form of self-chosen end of life, which is virtually identical to the Committee majority's proposal for self-chosen and self-executed end of life for terminal people, see *section 3 Majority Proposal*, and the same applies to approximately 67% of healthcare professionals in England. See for example Lynøe, N., et al, (2021). Trends in Swedish physicians' attitudes towards physician-assisted suicide: a cross-sectional study, *BMC Med Ethics* og Ibbetson, Conner. (2020). Do people in the UK support euthanasia? YouGov. 21 January.

[36] Blendon, R. J., Benson, J. M., & Hero, J. O. (2014). Public trust in physicians—US medicine in international perspective. *The New England Journal of Medicine*, 371(17): 1570-1572.

3. Majority Proposal

Addendum to current legislation

3.1. Appendix 1 - Self-chosen[37] and self-executed end of life for terminal people

A majority of the Committee proposes that every terminal person has the right to medically prescribed medication for self-chosen end of life if the following conditions are met:

1. The person who wishes to end their life must explicitly express this wish in a way that leaves no doubt that this is what that person wants.
2. At the time of the request, the person must be of legal age and competent.
3. The person's decision must be based on an informed healthcare basis, including other relief options.
4. The person must have a remaining life expectancy of no more than 6 months.
5. End of life must be carried out by the person themselves, provided that medication and relevant knowledge are made available by healthcare professionals.

Kim Oskar Bakbo-Carlsen and Janne Rothmar Herrmann concur.

3.2 Appendix 2 - Self-chosen and assisted end of life for terminal people

Some Committee members also suggest that it should be possible to receive assistance with executing the actual end of life.
This appendix includes all points 1-5 and a 6th point.

6. If the person wants to end their life but is unable to do so themselves, they can get help from a healthcare professional. It must be ensured that the person administering the end-of-life medication does so voluntarily.[38]

Camilla Thorn Kristensen, Thomas Søbirk Petersen, Lars Lior Ramsgaard, Kirsten Jacobsen and Kathrine Lilleør concur.

3.3 Monitoring practice

For both appendices, the prescription of end-of-life medication must be registered and reported to the authorities to ensure monitoring of the practice.

Committee members in favour of Appendix 2 believe that Appendix 2 is better than Appendix 1. However, if the choice is between current legislation and Appendix 1, those Committee members in favour of Appendix 2 believe that Appendix 1 is preferable to current legislation.

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[37] The majority of the Committee believes that 'self-chosen end of life' are words that more accurately capture what the majority of the Committee wants to discuss here rather than the words 'active, assisted death'. Traditional palliation is also characterised by active actions (e.g., turning off a ventilator, increasing a dose of morphine). But more importantly, 'active, assisted death' does not directly say anything about who should have access to end of life. Instead, the majority of the Committee believes that the words 'self-chosen end of life for terminal patients' capture this – the patient who wants to end their own life.

[38] A parallel can be drawn to the abortion regulation where healthcare professionals have the right to ethical reservations, see section 102 of the Danish Health Act (sundhedsloven). As the right to early abortion is formulated as a legal right, there is an obligation to refer to another doctor without ethical reservations, and it is the responsibility of the region to employ a sufficient number of healthcare professionals without ethical reservations to fulfil this legal requirement.

4. Minority reflections

4.1 Palliation and existing options for relief and self-determination

The prerequisite for talking about a more dignified death is that decision-makers and authorities show willingness to promote dignity in lives with life-threatening illness. The Committee's minority believes that palliative care today is not sufficiently accessible and adequate for everyone in need. This may mean that death and life with a life-threatening illness are not seen as dignified among a group of people in Denmark.

With many people living longer with life-threatening illnesses, palliative care is expected to play an increasingly important role in the future, starting earlier in the course of the illness. Internationally, it is recommended that palliative care should be initiated at the onset of illness, which means that palliative care is not just for people who are dying.[39]

WHO defines palliative care as follows: "*Palliative care aims to promote the quality of life of patients and families facing the problems associated with serious illness. This is done by preventing and relieving suffering through the early identification, immediate assessment and treatment of pain and other problems, whether physical, mental, psychosocial or spiritual.*"[40]

Palliation is about helping people with life-threatening illnesses to live the best possible life until death, despite suffering. People with life-threatening illnesses can achieve relief through a palliative approach that focuses on physical, mental, social and spiritual/existential conditions – for example through presence, dialogue and other forms of palliative care. Relief is not just about the person with a life-threatening illness – relatives also need support and care as the experience of seeing a loved one suffer due to a life-threatening illness can be intensely stressful.

That is why palliative care needs to be improved in Denmark. The crucial first steps to supporting both basic and specialised palliation are to ensure a higher level of peace of mind in being able to receive competent and adequate care. For example, by ensuring that all people with life-threatening illnesses have access to specialised healthcare assistance within palliation at all hours. The best possible life until death despite suffering calls for the best possible relief of suffering from the moment the suffering occurs, not only in the very last part of life. A dignified end of life requires a high level of individualised care, treatment and attention. It requires a high level of professional palliative competences among all healthcare professionals working with people with serious illnesses. Many comprehensive options for relief and a high degree of self-determination already exist but are not being fully utilised today. Examples are:

- That the citizen refrains from attempting resuscitation in a current medical situation.
- That the citizen renounces any form of disease treatment and preventive treatment.
- That staff refrain from initiating life-prolonging treatment if it is deemed futile.
- That staff discontinue ongoing life-prolonging treatment if it is deemed futile.
- That staff provide the palliative medication needed to achieve adequate symptom relief.

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[39] World Health Organization (2023). Palliative Care.
[40] World Health Organization (2023). Palliative Care.

- That staff provide palliative sedation (lowering the level of consciousness) for unbearable suffering that cannot be relieved by other means in the final moments.
- That citizens over 60 years of age waive resuscitation attempts in the event of cardiac arrest when the scheme comes into force (from 15 January 2025).

It is the minority's opinion that the options described, including that palliation in the future should be offered both early in the course of an illness and at the end of life, are currently not sufficiently known by professionals and the population. In addition, there is a lack of distribution to all relevant illness groups. This means that there is a risk that palliative treatment is initiated too late or not at all in the course of a person's serious illness. Similarly, there needs to be a broader understanding among healthcare professionals and the public that palliative treatment is also an active treatment choice that is not curative, but relieving, and can be provided alongside curative treatment, life-prolonging treatment or as the only treatment.

4.2 The current organisation and understanding of palliation in Denmark is predominantly aimed at people who are dying soon

There is untapped potential in spreading the palliative approach much earlier in the course of illness, as recommended internationally.[41] This is to ensure relief when suffering occurs and to provide the right support and care for relatives. The approach will cater to people suffering from life-threatening illness and support those affected to experience *dignity*, which is a key concept in palliation.

The minority notes that Rigsrevisionen has previously criticised access to specialised palliation in August 2020. The Ministry of the Interior and Health of Denmark and the regions have since launched initiatives to ensure timely and equal access to specialised palliation. A number of these initiatives are recent, and some are still being developed or implemented.

There is potential in increasing the knowledge of healthcare professionals across professions and sectors to identify suffering and needs and partly developing competences to relieve suffering where it is needed. One of the major challenges is how to ensure systematic identification of suffering and ensure that the right competences are in place when the need arises.

In this context, it is important that competent palliative care, attention and treatment are independent of the diagnosis, and it must be a natural and integral part of all treatment of people with life-threatening illnesses. This could lead to better relief and less suffering while people with life-threatening illnesses and their families could become a more important part of assessment and treatment planning. Research[42] suggests that this will lead to a reduction in futile diagnosing and treatments, which will support a more dignified death based on the self-determination of those involved.

"*For example, when a person with advanced terminal dementia continues to receive life-prolonging treatment in the form of tube feeding or antibiotics for infections, the natural death of dementia is delayed. Talking to relatives about the wishes that the patient has previously expressed if they were to find themselves in this situation, what treatment is meaningful and what relief can be provided - so that there is no discomfort at the end of life - may create confidence to opt out of futile life-prolonging treatment,*

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41 Ibid.
42 Ibid.

which is often provided when we don't talk about other options that exist for relief in the natural course of the illness."[43]

4.3 Training in palliative care and supervision can ensure better and more uniform relief for everyone who needs it in Denmark

Today, there are major differences in the distribution of professional groups and resources in the primary and secondary sectors, which also applies to palliative care. This is seen as one of the major challenges in ensuring dignified life and death – across diagnoses and sectors.

To ensure that living *with* and dying *from* life-threatening illness is done with more individualised choices and dignity, rethinking the overall allocation of resources to better education, training and supervision is required.

A dignified life with life-threatening illness can be significantly improved by strengthening the *education* and *supervision* of all professions, including social and healthcare workers and care assistants, who care for people in the "front line", i.e., in homes and nursing homes. Many people want to stay and even die in their own home, see DaneAge's survey of Danes' attitude to death from 2018[44]: "*Danes' attitude to talking about their own and their loved ones' final days and death*", and palliative care should therefore be taken to that point. A higher level of education and offering ongoing training and supervision can strengthen the use of palliation by staff across sectors. A better professional staff will be able to provide better treatment and care. This could lead to more people, despite life-threatening illness, experiencing their life as dignified until death.

There is a need to ensure a more uniform understanding of palliation across professions. If all professions working with people with life-threatening illness had a common professional language around identifying and relieving suffering, compassionate relief could become as common as changing dressings or dispensing medication. By ensuring that everyone working with people affected by life-threatening illness is trained to relieve physical, mental, social and spiritual/existential suffering, this important, compassionate part could become standard and would be a big step towards a more dignified life with life-threatening illness, thus a more dignified death than today.
Today, there is no common professional language for palliation and relief. There are currently no common, recognised standards for what constitutes good professional treatment and care across professions and sectors. However, in 2017, the Danish Health Authority published "Recommendations for palliative care". [45][46]

And in early 2023, the regions worked with the Danish Society for Palliative Medicine and established a specialised training programme in palliative medicine. With this training, medical specialists working in specialised palliation can now be trained as subject area specialists in palliative medicine. The programme is expected to eventually be open to a wider range of doctors. However, there currently is no officially recognised specialist training in palliation for nurses, social and healthcare assistants, physiotherapists, occupational therapists, social workers and others. And palliative medicine in Denmark

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[43] Neergaard A.M., Helledie E., Jørgensen B., Mathiesen H., Nielsen K. M. (2024). Danish consensus term and definition for Advance Care Planning (ACP): Wishes for Future Care and Treatment (FPB).

[44] Nørregård-Nielsen, E. (2018). Danes' attitudes towards talking about their own and their loved ones' final days and death. DaneAge Association (Ældre Sagen).

[45] The Danish Health Authority (2017). Recommendations for palliative care.

[46] The Danish Health Authority has published recommendations for palliative care for children. See 'Recommendations for palliative care for children, adolescents and their families', the Danish Health Authority 2018.

is not an independent medical speciality as is the case in countries with which we normally compare ourselves.[47]

"*The lack of sufficient knowledge and sufficient healthcare professional competences to provide optimal symptom relief and palliative sedation can lead to unnecessary fear of experiencing unbearable suffering, such as the fear of death by suffocation or unbearable pain.*"[48]

The Committee's minority is of the opinion that specialisation in all areas of healthcare is an essential prerequisite for ensuring adequate training, professional development, research and thus ensuring a continuous general competence boost. The lack of an adequate national training strategy in this area should be a cause for reflection.

4.4 Better organisation can bring more dignity to life with life-threatening illness

In the opinion of the Committee's minority, the challenges described within current palliative care can create unnecessary insecurity, suffering, loss of quality of life and thus a risk of undignified life and death.

One of the challenges in basic-level practice is that there often is a lack of sufficient[49] and urgently available information about an individual's health and treatment level which may lead to the initiation of unwanted treatment. This could be attempted resuscitation in case of cardiac arrest.

The primary care sector today cannot see what has happened in the hospital, and the hospital cannot see what has been done and assessed in the primary care sector. A lot of communication in the healthcare system is based on short messages back and forth. Across hospitals, general practice and municipalities, no one has a complete overview of the sick person's progress. Therefore, several hospices are working on developing a communication tool that is not linked to Sundhedsplatformen.

Information available across sectors on a common platform, which does not exist today, could prevent the risk of receiving futile and unwanted treatment.

Furthermore, a significant challenge is that it can be difficult to get sufficient and accessible help from the specialised palliative level. Experience of healthcare professionals shows that this negatively affects patients, relatives and staff working in the primary care sector.[50]

According to the above 2018 survey by DaneAge, most people in Denmark want their lives to end in their own home, and it is therefore crucial that the possibility of dignified care and relief is ensured regardless of where the patient is staying.

It is the opinion of the Committee's minority that the patient's own doctor, district nurses and care assistants, who are often the primary healthcare co-ordinators when people with life-threatening illnesses stay in their own homes, do not currently have sufficient opportunities and resources to ensure

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47 Arias-Casais N, Garralda E, Rhee JY, Lima L de, Pons JJ, Clark D,Hasselaar J, Ling J, Mosoiu D, Centeno C. (2019). *EAPC Atlas of Palliative Carein Europe 2019*. Vilvoorde: EAPC Press.

48 Sundhed.dk. (2024). Medical treatment of patients facing inevitable death. 29 February.

49 Sundhed.dk. (2024). Patientsikkerhedsnyt – February 2024. 13 February.

50 REHPA. (2020). Mapping rehabilitation and palliation in Denmark.

optimal care and treatment, even though the vast majority of people with life-threatening illnesses can receive relief in the primary care sector with the right initiatives.

It is the minority's opinion that when primary care sector staff treat patients with life-threatening illnesses, it is rarely possible to have direct contact with a doctor trained with relevant professional competences in palliative medicine, and this can create insecurity and dissatisfaction for patients and relatives. It can also lead to an increase in dissatisfaction and powerlessness for the nursing staff, who may feel that they are unable to deliver proper palliative care. In addition, the Danish Health Authority has stated that there is not sufficient widespread access to specialist counselling around the clock.

As a result, people with life-threatening illnesses may instead be taken to an emergency department for hospitalisation or other, often futile, treatment. Instead of dying a calm and dignified death, a person may end up with a long, complicated process that neither they nor their loved ones experience as a dignified end of life.

This could be significantly optimised if primary care sector staff had direct contact with competent healthcare professionals and the ability to both quickly change medicine and start palliative care medicine and if access to palliatives in the primary care sector was guaranteed. One benefit would be that relatives would not have to drive far to pick up medicine from the nearest 24-hour pharmacy in an emergency situation.

To ensure access to medicine around the clock, it is necessary to rethink the organisation of medicine for district nurses and access to competent round-the-clock medical support. All people with life-threatening illnesses, regardless of whether they are receiving specialised palliation, should have this option. It should be considered whether a few simple steps can create better conditions for providing the best relief in the primary care sector. Introducing the concept of "tryghedskasser" (palliative care kits) would be a small but effective step.

4.5 Dignity and self-determination for people suffering from life-threatening illness

There are many untapped opportunities to ensure both timely and sufficient relief that will also support a high level of self-determination and thus a more dignified life with life-threatening illness. Self-determination comes as a natural consequence of the focus in the palliative approach on which involves the patient and relatives in a caring and realistic discussion of available options.

Research[51] shows that futile treatments are often rejected while quality of life improves. This applies to both people affected by life-threatening illness and their relatives. It could be considered whether the fear of receiving unwanted treatment or being kept alive contrary to the patient's wishes can be strengthened through this involvement.

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[51] Temel, J. S., et al, (2010), Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer, *The New England Journal of Medicine,* 363(8): 733-742
Benthien, K. S., et al, (2018), Is specialized palliative cancer care associated with use of antineoplastic treatment at the end of life? A population-based cohort study, *Palliative Medicine*, 32(9): 1509-1517.
Matsumoto, Y., Higuchi, A., Shiba, M., Sasaki, K., Saiki, T., Honma, Y., Kimura, K., Zhou, Q. and Saijo, Y, (2023), Termination of Palliative Chemotherapy Near the End of Life: A Retrospective Study of Gastrointestinal Cancer Patients*, Palliative Medicine Reports*, 4(1): 169-174.

5. Minority Proposal

A more dignified death in continuation of the Danish tradition of care and treatment of life-threatened and non-life-threatened patients and its possibilities and potentials

5.1 A more dignified death for terminally ill people

Talking about a dignified death without talking about dignity in life is meaningless. Dignity in life is the prerequisite for a dignified death. As a society, we must be able to grasp each individual person's life with care, support and nursing when needed to create the best possible conditions for a dignified life, thus a dignified death. If people have had the best conditions to create a dignified life – including in the last part of life – death will be experienced as all the more dignified.

In Denmark, people die as a result of old age, accidents or illness. The treatment offered aims to heal or relieve. This is the legal, ethical and healthcare foundation on which we have built our care and treatment. Danish patients have the right to decline offered treatments and to discontinue treatments they are currently undergoing. These patient rights are created to ensure that patients are not kept alive against their wishes or receive treatment they do not want. If the end of life is painful, patients have the right to palliative treatment, which aims to relieve suffering.

These conversations between the patient, their family and the healthcare professional are difficult but may be crucial in preventing overtreatment and allowing the patient to make peace with their fate and face death with more confidence and less fear. One conversation tool for this is Advance Care Planning (ACP).

A broad, legal framework for medical treatment at the end of life, for opting in and out of treatment, a broad framework for self-determination and room for the involvement of extensive, professional competences and treatment options already exist. In the opinion of the minority, there are many and extensive possibilities for relief and a high degree of self-determination that can be utilised even more today – for example through increased awareness among the population and professionals. Examples are:

- That the citizen refrains from attempting resuscitation in a current medical situation.
- That the citizen renounces any form of disease treatment and preventive treatment.
- That staff refrain from initiating life-prolonging treatment if it is deemed futile.
- That staff discontinue ongoing life-prolonging treatment if it is deemed futile.
- That staff provide the palliative medication needed to achieve adequate symptom relief.
- That staff provide palliative sedation (lowering the level of consciousness) for unbearable suffering that cannot be relieved by other means in the final moments.
- That citizens over 60 years of age waive resuscitation attempts in the event of cardiac arrest when the scheme comes into force (from 15 January 2025).

However, with the right initiatives, this framework can be strengthened and must be utilised even more in the future so that Danes can achieve a more dignified death.

In 2024, the Danish Medical Association conducted a study[52] showing that only one in five Danes actually know what active, assisted death is and confuse legal and applied forms of treatment and opting out of treatment with active, assisted death. This emphasises the need to spread knowledge about the already numerous and extensive options for relief and self-determination to both professionals and the general public.

Palliative care in Denmark can and must be improved. This applies to basic palliation as well as specialised palliation. Among other things, this can be done through the following initiatives taken from the Danish Society for Palliative Medicine's Strategy from 2024[53]:

- Dedicate resources to early, multidisciplinary, needs-based care and treatment, regardless of location and diagnosis.
- Establish adequate training of healthcare professionals in palliative care and specialisation within palliation, including the establishment of a medical speciality in palliation.
- Create 24/7 access to counselling and guidance from healthcare professionals to healthcare professionals with the right competences within palliation.
- Ensure patient and family involvement in decisions about future care and treatment.
- Ensure sufficient and up-to-date cross-sectoral information about health, treatment wishes and treatment level.
- Ensure access to palliative medicine in emergency situations – in the primary care sector.

5.2 A more dignified death for people with non-life-threatening illnesses

People in Denmark who do not die from serious illness and may not need palliative medicine may still need care and attention. In their 2022 report on care in the Danish healthcare system, the Danish Council on Ethics has described that there is a need for care in the healthcare system to not only be offered when there is a benefit, but it should be considered a fundamental approach in everything the healthcare system does.[54]

Opportunities for ordinary compassionate end-of-life care and nursing for vulnerable people in Denmark, including some elderly, nursing home residents and physically or mentally disabled people, are not always satisfactory today. This topic has been described and debated repeatedly in the media. Life, and the end of life, can therefore feel frightening and undignified for a person who is dependent on the help of others in a situation where options for help are limited.

A study from the Danish Health Authority (2022) on how municipalities implement dignity policies shows that "a dignified death" is the theme that the fewest municipalities have chosen as a special focus area. Therefore, a risk exists that dignity in death is also given a low priority[55].

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[52] Danish Medical Association (2024). Active, assisted death.
[53] Danish Society for Palliative Medicine (2024). National strategy for palliative medicine 2024.
[54] The Danish Council on Ethics (2022). Caring in healthcare: Report.
[55] The Danish Health Authority (2022). Municipalities' experiences with dignity policies – a study of the work of developing and implementing dignity policies.

A dignified end of life requires a high level of compassionate, individualised care, nursing and treatment regardless of whether the end of life occurs as a result of natural ageing, debilitation or illness.

Ensuring that living *with* and dying *from* serious illness or ageing is done with more individualised choices and dignity requires new thinking on education, organisation and prioritisation of resources for compassionate care and nursing regardless of location and across diagnoses and sectors.

Based on the minority's reflections, here are two suggestions on how to ensure a more dignified end of life – in addition to the options that already exist today.

Suggestions:

To ensure a higher level of confidence in receiving competent and adequate care by introducing patient rights within palliation. For example, all people with life-threatening illnesses have the right to 24-hour access to specialised healthcare assistance within palliation. The Committee's minority notes that the Danish Health Authority has an addressed focus on the area.

To strengthen palliative training for healthcare professionals who are not doctors.

5.3 Refusing the possibility of assisted suicide and active assisted death

Regardless of whether it is categorised as self-chosen and self-executed end of life, the assistance of others with the intention of ending a person's life is currently criminalised in sections 239 and 240 of the Danish Penal Code (straffeloven). It is called active assisted death and assisted suicide.

The decisive factor in criminalisation is that there is intent to end a person's life. Motivation can take many forms, but the action of the other person is aimed at ending life. Not to provide relief. This is the crucial difference between assisted death and palliation.

By involving someone else to fulfil the wish to die, the legislator has to set criteria for the target group and set the framework to decriminalise the assistance. In this context, assessment of life and life value will be key elements. If the demarcation is to be diagnosis-based, it must depend on the remaining life expectancy and how to assess that... or could one imagine that only a subjective assessment of life fatigue would be needed to get help to die?

All criteria will include an assessment that the lives of the target groups involved are recognised as unworthy and therefore worthy of ending with the help of society. It cannot be ruled out that target groups such as people with physical or mental disabilities will be included sooner or later. In this situation, there are two reasons why assisted death cannot be introduced.

Firstly, the mere fact that it cannot be ruled out that these target groups are included is sufficient to prevent assisted death from being introduced. The reasoning behind this is that one or more groups of people with access to assisted death risk being categorised as unworthy, thus labelled as less valuable than others.

Secondly, this categorisation means that people in the target groups who live a good life and do not want assisted death risk feeling both stigmatisation and pressure to consider assisted death in line with those in the target groups who want assisted death.

Many argue in favour of assisted suicide in the form introduced in the US state of Oregon saying there has not been an unwanted shift in the framework since the introduction of the offer. In the opinion of the minority, this is not correct. The article "*Oregon Death with dignity Act access: 25-year analysis*" shows that several things have changed in Oregon[56]:

1. The reason for wanting assisted suicide:
   - Several state as their reason that they feel like a burden.
   - Several state as their reason that they have financial concerns.
2. The relationship between the doctor and the patient:
   - The time during which the doctor knows the patient before prescribing the lethal drugs has decreased from 18 weeks to five weeks (problematically short given that hopelessness and depression can influence the death wish and are often overlooked by doctors, making intervention impossible).
3. Exemptions and changes to diagnoses that may qualify for assisted suicide:
   - There has been an increase in the number of exemptions from the 15-day reflection period.
   - Since 2010, patients with diagnoses that are not directly life-threatening have received assisted suicide – such as complications from falls, hernia, arthritis and anorexia.

Additionally, those referring to the Oregon model argue that it will not affect the doctor-patient relationship when the doctor only prescribes the drug and is not present at the time of the suicide. This and organisational experiences and concerns are described in the article "*Assisted dying and medical practice: questions and considerations for healthcare organisations*"[57]:

- In Canada, doctors withhold relieving medication out of concern that sedation could affect the patient's ability to consent to assisted suicide, even if it could offer relief to the patient.
- In Canada, this has impacted the doctor-patient relationship in that patients are concerned that doctors will encourage them to an accelerated death.
- In Oregon, complication rates have been as high as 14.8% with vomiting, seizures and reawakening. The time it takes to die ranges from one minute to 104 hours with an average of
- 50 minutes.

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[56] Regnard, C., Worthington, A., & Finlay, I. (2023). Oregon Death with Dignity Act access: 25 year analysis. *BMJ Supportive & Palliative Care*, 14: 455-461.

[57] Worthington, A., Finlay, I., & Regnard, C. (2023). Assisted dying and medical practice: questions and considerations for healthcare organisations. *BMJ Supportive & Palliative Care*, 13(4): 438–441.

6. The Committee's joint proposal

6.1 The overall Committee's proposal

The Committee for a more dignified death has noted that in 2017, the Danish Health Authority made a number of recommendations for palliative care.[58] The recommendations are based on the current knowledge and legislation in the field at the time and have been qualified by a working group appointed by the Danish Health Authority.

The Committee notes that Rigsrevisionen previously criticised the right to specialised palliation in August 2020. The Ministry of the Interior and Health of Denmark and the regions have since launched initiatives to ensure timely and equal access to specialised palliation. A number of these initiatives are recent, and some are still being developed or implemented.

The Committee also notes that the Danish Health Authority is currently preparing a technical proposal for a future Cancer Plan V, which will include recommendations for strengthening the palliation area.

6.2 The Danish Health Authority's recommendations for palliative care

According to the report, the purpose of the recommendations from the Danish Health Authority was to create equal access to palliative treatment throughout the country regardless of the diagnosis and to improve the quality of care, especially in relation to basic palliative care. The recommendations summarised here only address palliative care for adults.[59]

The recommendations from the Danish Health Authority address different aspects of palliative care and are therefore categorised accordingly. The recommendations are summarised in the following. The individual recommendations are detailed in the Danish Health Authority's 2017 report.

6.2.1 The palliative process

The report[60] emphasises that the goal of palliative care is to relieve the suffering of the patient and their relatives, regardless of whether the suffering is physical, mental, social and existential/spiritual in nature. See chapter *7. List of definitions* for examples of palliative care.

The following recommendations from the Danish Health Authority address the holistic perspective on the needs and problems of patients and relatives in connection with life-threatening illness:

- Everyone with a life-threatening illness, regardless of diagnosis and age, is offered palliative care based on the individual's needs.
- The palliative process is organised and carried out individually and in collaboration with the patient and relatives based on a professional holistic approach and with the greatest possible continuity of associated professionals.

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[58] The Danish Health Authority (2017). Recommendations for palliative care.

[59] In 2018, the Danish Health Authority issued recommendations for palliative care for children. See 'Recommendations for palliative care for children, adolescents and their families', the Danish Health Authority.

[60] The Danish Health Authority (2017). Recommendations for palliative care: 14.

- Identification and assessment of the patient's need for palliative care is based on a holistic approach and the individual patient's prerequisites; it takes place as early as possible, preferably at the time of the diagnosis, and systematically using uniform and validated tools across sectors and is repeated as needed.
- Palliative care includes work in relation to physical and psychological symptoms as well as social and existential/spiritual conditions as needed. In addition, care in relation to relatives and those left behind.
- Everyone with a life-threatening illness is offered systematic dialogue about future treatment and care.

6.2.2 Organisation, responsibility and collaboration

According to the report[61], the overall goal of palliative care is to be able to offer patients with palliative needs and their relatives palliative care of high professional quality adapted to the individual, regardless of the diagnosis and where the patient is in the course of their illness and where the patient is typically located. It is emphasised[62] that it is a management responsibility to ensure the quality of palliative care, including the availability of necessary resources and competencies. The Danish Health Authority has made the following recommendations aimed at the organisation of, responsibility for and collaboration on palliative care:

- The organisation of all palliative care is based on having the necessary and appropriate knowledge, routine, experience and volume as well as the necessary facilities to ensure that the care can be provided with high professional quality and continuity. Care is provided at the lowest possible effective level of care and treatment and is based on flexibility in terms of where the care is provided so that the patient can, for example, be hospitalised or discharged depending on where their needs are best met at the relevant point in time.
- Palliative care is carried out in interdisciplinary, team-based collaboration.
- Healthcare professionals and other professionals in all sectors are aware of and inform patients and relatives about relevant palliative services in, e.g., patient organisations, among volunteers etc.
- Hospital departments hold multidisciplinary team conferences (MDT conferences) between the relevant specialities and representatives from specialised palliative care to discuss specific patient cases, including communication and coordination with relevant actors in the municipality and general practice, regardless of the diagnosis.
- Municipalities and regions, including general practice, arrange interdisciplinary meetings under the auspices of healthcare agreements and practice plans, and the various actors meet face-to-face or via video calls to discuss collaboration and coordination of care.
- Under the auspices of healthcare agreements and practice plans, municipalities and regions, including general practice, prepare joint objectives for interdisciplinary and cross-sectoral collaboration based on the patient's needs, existing activities and the patient's (and relatives') resources.
- If necessary, a coordinating meeting is held in the patient's home with the participation of the patient, relatives, the GP and district nurse as well as other relevant parties.

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[61] Ibid: 21.
[62] Ibid: 22.

6.2.3 Training, competences and research

The report emphasises[63] that the necessary competencies must be in place to ensure high professional quality in palliative care. Relevant training and competences are therefore important for healthcare professionals and other professionals to be able to deliver professional palliative care, both in relation to patients and relatives and in the form of supervision of staff. At present, recruiting staff with sufficient palliative competences is generally perceived as difficult. Healthcare professionals need specific competencies at specific levels in order to provide basic and/or specialised palliative care.

The Danish Health Authority has made the following recommendations to ensure high professional quality within palliative care, especially in relation to training and competences:

- Palliative care is included in all pre- and postgraduate healthcare training programmes.
- All healthcare professionals and other professionals working with basic palliative care (in hospitals, municipalities and in the practice sector) have at least pre-graduate basic level competences (level A), and all hospital departments and municipalities have healthcare professionals in each profession with post-graduate basic level competences (level B).
- Basic care providers have access to round-the-clock advice from specialised care providers. Care is managed in collaboration with the patient's own doctor.
- Specialised palliative care units (palliative team, palliative ward and hospice) generally comprise four professionals, including at least one doctor who is a specialist in the field and one nurse with post-graduate, specialised level (level C) competencies – both of whom must be employed full-time in palliative care. The other professions can contribute part-time.
- Healthcare professionals working with basic and specialised palliative care can involve other relevant professionals.
- It is possible for the district nurse, GP and on-call doctor to contact palliative care staff on-call 24 hours a day for patients who are connected to a specialised palliative care unit but who are staying in their own home.

6.2.4 Monitoring and quality assurance

In the report, the Danish Health Authority[64] discusses the potential of monitoring palliative care as the ideal monitoring, according to the report, will provide knowledge about the incidence of palliative needs in relevant patient groups, will be able to describe the scope, nature and effect of palliative care carried out throughout the healthcare system and provide a basis for assessing the quality of palliative care - both in terms of professional, organisational and patient-perceived quality.

In addition, the report[65] emphasises the importance of continuously performing quality assurance on the palliative care field across sectors and that it should be considered how to expand the group of patients for whom systematic quality monitoring is carried out.[66] The report mentions various tools that can be used to identify patients' palliative needs.

Based on these considerations, the Danish Health Authority recommends the following:

- Data and indicators are reported in the Danish Palliative Database for specialised work for all life-threatening illnesses.

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[63] Ibid: 27.

[64] Ibid: 30.

[65] Ibid: 31.

[66] Since the publication of the Danish Health Authority's Recommendations for Palliative Care, an indicator, indicator 3, has been added to the Danish Palliative Database's set of indicators regarding non-cancer patients who are in contact with specialised palliative care before death (indicator 3).

- Municipalities and regions register all patients who have their palliative care needs systematically identified.
- Regions and municipalities develop a common form under the auspices of healthcare agreements and practice plans that can be used across sectors to systematically identify patients' palliative needs.

The Committee agrees with the recommendations of the Danish Health Authority.

6.3 The Committee's joint proposals

The prerequisite for talking about a more dignified death is that decision-makers and authorities show willingness to promote dignity in lives with life-threatening illness. Palliative care today is not available and sufficient for everyone in need. Therefore, death and life with life-threatening illness is not perceived as dignified enough among a group of people in Denmark.

The Committee believes that it is crucial to support both basic and specialised palliation and proposes the following:

- That the citizen (a proxy) can choose that the next of kin (a proxy holder) in the situations below can also decide to opt out or discontinue life-prolonging treatment when the citizen is no longer able to fulfil their own wishes. It is intended to complement the existing system of advance medical directives. See further details below *in section 6.2.5 The advance medical directive scheme and the Committee's recommendation to supplement it.*
- To increase the availability of competent and adequate relief by strengthening the palliative training of healthcare professionals and other professionals.

6.3.1 The advance medical directive scheme and the Committee's recommendation to supplement it

In an advance medical directive scheme, any person of legal age can express their wishes with regard to treatment if they find themselves in a state where their right to self-determination cannot be exercised, i.e., if they become legally incompetent. The advance medical directive scheme is a binding specific advance declaration to healthcare professionals to reject or discontinue life-prolonging treatment in three specific future health situations.

The advance medical directive allows the patient to decide what happens in the following situations:

- If the patient is dying and the treatment will only prolong the patient's life but will not make them feel better or relieve their pain.
- If the patient is so weakened by illness, accident or age that they will never again be able to care for themselves physically or mentally.
- If the treatment could mean that the patient would survive but the doctor believes that the physical consequences of the illness or the treatment itself will be very serious and distressing.

For example, all competent citizens over the age of 18 can reject resuscitation attempts in advance by creating an advance medical directive with binding effect for healthcare professionals in a possible future situation.

The advance medical directive scheme currently allows for advance declarations to opt out of treatment subject to the consent of the relatives, guardian or proxy. This applies to the last two situations above.

The Committee's proposal is to introduce an additional declaration option in the advance medical directive stating that the nearest relatives can be the ones to make decisions about rejecting or discontinuing life-prolonging treatment in all three specific future health situations covered by the advance medical directive. This means that the patient will not make an advance decision independently but will leave it to the nearest relatives by explicitly stating it in an advance medical directive. In other words, the nearest relatives *can*, but are not required to, make a decision to reject life-saving treatment.

6.3.2 Improving access to relieving medication in the primary care sector

The Committee also proposes the reintroduction of so-called "palliative care kits" as a concept for palliative treatment. Prescribed by a doctor, the palliative care kit can help ensure that relevant medication is available in a timely manner to relieve the symptoms of dying patients. The palliative care kit contains medication for a short period of time, e.g., the first 24 hours, after which the medication must be re-prescribed. It can be placed with the patient in their own home or in a nursing home. Following a doctor's prescription, the medication can be administered by, for example, a district nurse to relieve symptoms of the dying patient when needed. It can therefore also prevent hospitalisation in the final stages for patients who wish to die at home/at a nursing home.

The Committee believes that the availability of the palliative care kit will create a higher level of security for healthcare professionals, citizens and relatives. In that regard, the Committee believes that it would be beneficial for palliative care kits to be available at nursing homes or home care units. This makes it faster to treat palliative or terminal citizens with exactly the medication they need. According to the Committee, this will be of particular benefit to remote areas of Denmark where it is challenging for staff and relatives to get hold of the relieving and necessary pharmacological agents.

6.3.3 Non-pharmacological relief and care in the primary care sector

The Committee also proposes the use of non-pharmacological relief and care in the primary care sector. Examples include music therapy, art therapy, therapy dogs, experiences in nature, teaching citizens meditation techniques, and grief support for citizens and relatives in nursing homes, homes and institutions. The latter would go a long way towards helping the dying person, their relatives and those left behind get help and support to manage everything from pre-loss grief, stress, reduce anxiety and provide space to address grief and concerns and thereby experience a more dignified end of life.

In conclusion, the Committee believes that palliative care in Denmark must be improved.

7. List of definitions

Below is the Committee's definition of key terms used in the reflection paper.

- **Serious illness**: Serious illness is when a person's everyday life is threatened and the illness causes major changes and role shifts between the ill person and their relatives. It can be severe physical and mental disabilities and/or a life-threatening illness. It also matters whether the illness is acute or chronic and the level of complex needs it causes.
- **Assisted end of life**: Assisted end of life is when a terminal patient who wants to end their life is assisted by a healthcare professional to administer a lethal agent prescribed by a doctor.
- **Indirect assisted death according to legislation**: Section 240 of the Penal Code states that anyone who contributes to someone taking their own life is punishable by a fine or imprisonment for up to 3 years.
- **Direct assisted death according to legislation**: Section 239 of the Penal Code states that anyone who kills another person at their specific request is punishable by imprisonment for up to 3 years.
- **Assisted death**: Assisted death is an act done at a person's request with the intention of causing that person's death.
- **Euthanasia**: Euthanasia is when someone else ends the life of a seriously ill person according to their wishes.
- **Competent**: Patients are competent when they have reached the age of 15 and can safeguard their own interests. This means that the patient can understand information, make rational judgements about treatment proposals etc. and understand the consequences of consent. A competent patient can give informed consent. Whether the patient can act reasonably in the specific situation is up to a healthcare professional's judgment.
- **Of legal age**: A person is considered an adult when they turn 18 years old and become legally competent in Denmark.
- **Palliative care**: The Danish Health Authority does palliative work aimed at promoting the quality of life of patients and families facing the problems associated with life-threatening illness by preventing and relieving suffering through early identification and immediate assessment and treatment of pain and other problems, whether physical, mental, psychosocial or spiritual.
    - **Basic palliation**: Basic palliation targets people with limited palliative needs in a few problem areas. Care can be integrated into the other care and treatment offered. Basic palliative care is provided by professionals in the healthcare system that do not have palliation as their main task. Basic palliative care is provided in most clinical hospital wards, in municipalities (e.g. home nursing and assisted living facilities) as well as in general practice and other practice sectors (e.g. psychologists and physiotherapists).
    - **Specialised palliation**: Specialised palliation targets people with palliative needs of high severity within individual problem areas and with multiple interconnected problem areas. Specialised palliative care is provided by professionals in those parts of the healthcare system that have palliation as their main task such as palliative

teams, palliative units in hospitals and hospices. Specialised care can take place during hospitalisation (e.g. in palliative care units and hospices), on an outpatient basis, in the patient's home/assisted living facility or in a hospital ward (via a palliative team).

- **Self-chosen end of life**: Self-chosen end of life is when a person's life ends because they want it to.
- **Dying soon**: A person is dying soon when the person is in a condition where it has been assessed that there is medical reason to provide immediate relieving treatment only, all other treatment is futile and death is expected within hours to a few days.
- **Terminal patients**: Patients are terminal when the doctor considers death to be inevitable.
    - **Terminal phase**: The terminal phase is the period when the patient's condition is characterised by severe physical debilitation and death is considered inevitable and the patient has a short life expectancy (hours, days or weeks).
    - **Terminal illness**: Terminal illness is an incurable and irreversible illness that has been medically confirmed and, within a reasonable medical assessment, will result in death within six months.
- **Inevitable death**: Death is considered inevitable for a patient when, according to medical judgement, death is highly likely to occur within days to weeks despite the use of treatment options that are possible based on the available knowledge of the underlying disease and its possible sequelae.
- **Incurable**: Incurable illness is a condition that cannot be changed and is therefore fatal. It is not possible to provide treatment that can cure or help the patient out of this condition. The condition can only be relieved and treated with palliation.

7.1 Examples of palliative care

The Danish Health Authority's Recommendations for palliative care from 2017 include an overall description of palliative care for physical and psychological symptoms as well as social and existential/spiritual conditions in Appendix 4. Here are a few examples:

<u>In case of physical symptoms</u>: Pharmacological and non-pharmacological work such as physiotherapy, occupational therapy and nursing. For example, palliative nursing may consist of fully assisting the patient with an activity, such as a bed bath when the strength for personal hygiene fails, treatment of wounds or supporting the patient in taking care of personal needs after initial assistance.

<u>For psychological symptoms</u>: Psychological distress in patients with life-threatening illness is a continuum from emotional reactions such as sadness and vulnerability to severe and disabling symptoms such as anxiety and depression. The emotional reactions are articulated to an extent that is agreed with and adapted to the patient and relatives. Support and empathetic communication is necessary for all patients, and some patients need or want counselling and treatment.

<u>In case of social conditions</u>: The aim of social care is to solve social problems, if possible, thus improve the patient's functional capacity and quality of life and reduce fear of the future. For some patients and relatives, the intervention will consist solely of counselling to enable them to make their own choices while others will need more care. Social work includes, among other things, providing information, preparing applications, creating an overview of social conditions, finding possible solutions and coordinating with other actors. For example, care can be in relation to the basis for support, help at home and information about circumstances in connection with death.

In case of existential/spiritual matters: Existential/spiritual care includes paying attention to the patient's existential/spiritual questions and resources, listening to the meaning they have in the patient's life story and assisting the patient in working with existential/spiritual matters based on their own view of life. Existential/spiritual care involves providing support to maintain previous attitudes and positions in life or providing support to adopt completely new perspectives from a new situation. It is possible to refer to a pastor or representative from other religious communities if the patient or relatives need it.

List of references

Arias-Casais N, Garralda E, Rhee JY, Lima L de, Pons JJ, Clark D,Hasselaar J, Ling J, Mosoiu D, Centeno C. (2019). *EAPC Atlas of Palliative Carein Europe 2019*. Vilvoorde: EAPC Press.

Benthien, K. S., Adsersen, M., Petersen, M. A., Vadstrup, E. S., Sjøgren, P. and Groenvol, M. (2018*)*. Is specialized palliative cancer care associated with use of antineoplastic treatment at the end of life? A population-based cohort study. *Palliative Medicine*, 32(9): 1509-1517.

BMA (2024). Key arguments used in the debate on physician-assisted dying. https://www.bma.org.uk/media/4394/bma-arguments-for-and-against-pad-aug-2021.pdf (10. december, 2024).

Blendon, R. J., Benson, J. M., & Hero, J. O. (2014). Public trust in physicians—US medicine in international perspective. *The New England Journal of Medicine*, 371(17): 1570-1572.

Chapple, A., Ziebland, S., McPherson, A., & Herxheimer, A. (2006). What people close to death say about euthanasia and assisted suicide: a qualitative study. *Journal of Medical Ethics*, 32(12): 706-710.

Cheung, G., Douwes, G., & Sundram, F. (2017). Late-life suicide in terminal cancer: A rational act or underdiagnosed depression? *Journal of Pain and Symptom Management*, 54(6): 835-842.

Dansk Selskab for Palliativ Medicin (2024). National strategi for palliativ medicin 2024. https://palliativmedicin.dk/wp-content/uploads/2024/04/DSPaM_National-strategi-2024.pdf (10. december, 2024).

Den Hartog, G. (2023). *What kind of death: The ethics of determining one's own death*. Routledge.

Det Etiske Råd (2023). Det Etiske Råds udtalelse om dødshjælp. https://etiskraad.dk/Media/638319994915209616/Det%20Etiske%20R%C3%A5ds%20udtalelse%20om%20d%C3%B8dshj%C3%A6lp%202023.pdf (12. december, 2024)

Det Etiske Råd (2022). Omsorg i sundhedsvæsenet: Redegørelse. https://nationaltcenterforetik.dk/Media/637997857938238345/DER_Omsorg%20i%20sundhedsv%C3%A6senet_2022_Redeg%C3%B8relse.pdf (12. december, 2024)

Frolic, A., & Oliphant, A. (2022). Introducing medical assistance in dying in Canada: Lessons on pragmatic ethics and the implementation of a morally contested practice. *HEC Forum*, 34(4): 307-319. Dordrecht: Springer Netherlands.

Ganzini, L., Goy, E., & Dobscha, S. (2009). Oregonians' reasons for requesting physician aid in dying. *Archives of Internal Medicine*, 169(5): 489–492.

Hartling, O. (2021). *Euthanasia and the ethics of a doctor's decisions*. Bloomsbury.

Hizo-Abes, P., Siegel, L., & Schreier, G. (2018). Exploring attitudes toward physician-assisted death in patients with life-limiting illnesses with varying experiences of palliative care: a pilot study. *BMC Palliative Care*, 17: 1-10.

Houska, A. & Loučka, M. (2019). *Patients' autonomy at the end of life: a critical review. Journal of Pain and Symptom Management*, 57(4): 835-845.

Ibbetson, Conner. (2020). Do people in the UK support euthanasia? YouGov. 21. januar. https://yougov.co.uk/health/articles/27240-public-and-healthcare-workers-support-euthanasia (10. december, 2024).

Indenrigs- og Sundhedsministeriet (2023). Kommissorium for Udvalget for en mere værdig død. https://www.ism.dk/Media/638331242652890272/Kommissorium%20for%20Udvalget%20for%20en%20mere%20v%C3%A6rdig%20d%C3%B8d_17.10.23.pdf (10. december, 2024).

Jessen, B. (2023). *Hjælp i den sværeste stund – når livet rinder ud*. Ugeskrift for Læger. 13. oktober. https://ugeskriftet.dk/nyhed/hjaelp-i-den-svaereste-stund-nar-livet-rinder-ud (10. december, 2024).

Krikorian, A., Limonero, J.T. & Maté, J. (2012). Suffering and distress at the end-of-life. *Psycho-Oncology*, 21(8): 799-808.

Lynøe, N., Lindblad, A., Engström, I., Sandlund, M. and Juth, N. (2021). Trends in Swedish physicians' attitudes towards physician-assisted suicide: a cross-sectional study. *BMC Med Ethics*, 22: 86.

Lægeforeningen (2024). Aktiv dødshjælp. https://laeger.dk/media/t4lgoxyp/laegeforeningens-undersoegelse-om-aktiv-doedshjaelp-2024.pdf (10. december, 2024).

Mantyh, P.W. (2014*)*. Bone cancer pain: from mechanism to therapy. *Current opinion in supportive and palliative care*, 8(2): 83.

Matsumoto, Y., Higuchi, A., Shiba, M., Sasaki, K., Saiki, T., Honma, Y., Kimura, K., Zhou, Q. and Saijo, Y, (2023), Termination of Palliative Chemotherapy Near the End of Life: A Retrospective Study of Gastrointestinal Cancer Patients*, Palliative Medicine Reports*, 4(1): 169-174.

Nielsen, A.K.B. (2022). 52-årige Winnie skal dø: Jeg synes, jeg har lidt nok. Sundhedspolitisk Tidsskrift. 19. december. https://sundhedspolitisktidsskrift.dk/nyheder/sundhedspolitik/7148-52-arige-winnie-vil-do-jeg-synes-jeg-har-lidt-nok.html (10. december, 2024).

Nørregård-Nielsen, E. (2018). Danskernes holdning til at tale om sin egen og sine næres sidste tid og død. Ældre Sagen. C:/Users/b213668/AppData/Local/Temp/MicrosoftEdgeDownloads/5b0289be-9c99-4d54-a78a-e82459801171/aeldresagen-rapport-2019-danskernes-holdning-til-at-tale-om-doeden.pdf (10. december, 2024).

Onwuteaka-Philipsen, B., Brinkman-Stoppelenburg, A., Penning, C., Jong-Krul, G., van Delden, J and van der Heide, A. (2012). Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990–2010: A repeated cross-sectional survey. *The Lancet*, 380: 908–915.

Oregon Health Authority (2023). Oregon Death With Dignity Act: 2023 Data Summary. https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year26.pdf (10. december 2024).

Petersen, T.S. & Dige, M. (2023). Critique of autonomy-based arguments against legalising assisted dying. *Bioethics*, 37: 165-170.

Regnard, C., Worthington, A., & Finlay, I. (2023). Oregon Death with Dignity Act access: 25 year analysis. *BMJ Supportive & Palliative Care*, 14: 455-461.

REHPA. (2020). Kortlægning af rehabilitering og palliation i Danmark. https://www.rehpa.dk/wp-content/uploads/2020/12/Rehpa-kortlaegning-rapport-FINAL-WEB.pdf (10. december, 2024).

Selskab for Sygeplejeforskning (2024). Dansk konsensus: Betegnelse og definition for Advance Care Planning (ACP) – ønsker for fremtidig pleje og behandling (FPB). https://sygeplejevidenskab.dk/index.php/2024/03/10/dansk-konsensus-betegnelse-og-definition-for-advance-care-planning-acp-oensker-for-fremtidig-pleje-og-behandling-fpb/ (10. december, 2024).

Neergaard A.M., Helledie E., Jørgensen B., Mathiesen H., Nielsen K. M. (2024). Dansk konsensus-betegnelse og definition for Advance Care Planning (ACP): Ønsker for Fremtidig Pleje og Behandling (FPB). https://sygeplejevidenskab.dk/index.php/2024/03/10/dansk-konsensus-betegnelse-og-definition-for-advance-care-planning-acp-oensker-for-fremtidig-pleje-og-behandling-fpb/ (10. december, 2024).

Suarez-Almazor, M. E., Newman, C., Hanson, J., & Bruera, E. (2002). Attitudes of terminally ill cancer patients about euthanasia and assisted suicide: predominance of psychosocial determinants and beliefs over symptom distress and subsequent survival. Journal of Clinical Oncology, 20(8): 2134-2141.

Sundhed.dk. (2024). Medicinsk behandling af den uafvendeligt døende patient. 29. februar.

https://www.sundhed.dk/sundhedsfaglig/laegehaandbogen/kraeft/tilstande-og-sygdomme/palliativ-medicin/medicinsk-behandling-af-den-uafvendeligt-doeende-patient/ (10. december, 2024).

Sundhed.dk. (2024). Patientsikkerhedsnyt, februar 2024. 13. februar. https://www.sundhed.dk/sundhedsfaglig/information-til-praksis/midtjylland/almen-praksis/regionalt/patientsikkerhed/info-om-patientsikkerhed/patientsikkerhedsnyt/ptnyt-februar-2024/ (10. december, 2024).

Sundhedsstyrelsen (2017). Anbefalinger for den palliative indsats. https://www.sst.dk/da/sygdom-og-behandling/~/media/79CB83AB4DF74C80837BAAAD55347D0D.ashx (10. december, 2024).

Sundhedsstyrelsen (2018). Anbefalinger for palliative indsatser til børn, unge og deres familier. *https://www.sst.dk/-/media/Udgivelser/2018/Anbefalinger-for-palliative-indsatser-til-b%C3%B8rn-unge-og-deres-familier.ashx?la=da&hash=F6076B69E176C370E193F4023B1ACB61E3A552D6* (10. december, 2024).

Sundhedsstyrelsen (2022). Kommunernes erfaringer med værdighedspolitikker – en undersøgelse af arbejdet med at udvikle og omsætte værdighedspolitikker til praksis. https://www.sst.dk/-/media/Udgivelser/2022/AEldre/VAERDIGHEDSPOLITIKKER.ashx?sc_lang=da&hash=6DE5F09C01A2C4312E564C2DE66D404F (10. december, 2024).

Temel, J.S., Greer, J.A., Muzikansky, A., Gallagher, E.R., Admane, S., Jackson, V.A., Dahlin, C.M., Blinderman, C.D., Jacobsen, J., Pirl, W.F., Billings, J.A. & Lynch, T.J., (2010), Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer, *The New England Journal of Medicine*, 363(8): 733-742.

Winzelberg, G.S., Hanson, L.C. & Tulsky, J.A. (2005). Beyond autonomy: diversifying-end-of-life decision-making approaches to serve patients and families. *Journal of the American Geriatrics Society*, 53(6): 1046-1050.

World Health Organization (2023). Palliative Care. https://www.who.int/europe/news-room/fact-sheets/item/palliative-care (10. december, 2024).

Worthington, A., Finlay, I., & Regnard, C. (2023). Assisted dying and medical practice: questions and considerations for healthcare organisations. *BMJ supportive & palliative care*, 13(4): 438–441.

Young, R. (2024). Voluntary Euthanasia. I Zalta, E.N. (red.) The Stanford Encyclopedia of Philosophy (winter 2024). https://plato.stanford.edu/archives/sum2024/entries/euthanasia-voluntary/ (3. september, 2024).

Appendix 1: The Committee's terms of reference

INDENRIGS- OG
SUNDHEDSMINISTERIET

Terms of reference for the Committee for a more dignified death

Introduction

We all have to go through it sooner or later. Saying goodbye to a loved one, a family member or a good friend. Some are ripped away from us before we had the chance to say goodbye. Others die peacefully in their sleep with the opportunity to have a say when it comes to the end of life. For some, death can also be a relief after a long period of time with pain. We all have to go through the end of life at some point in time. And whether it is us or someone close to us, we want it to be done with dignity.

The Danish government wants to initiate a dialogue with Danes about a more dignified death. A more dignified death is not only about how we leave this world but also about care in the final days. It will not be an easy conversation, but it is a conversation that must be had in the interest of individual self-determination.

The government has therefore set up the Committee for a more dignified death to moderate a collective social debate.

Purpose and work of the Committee

The purpose of the Committee is to initiate a dialogue with Danes about a more dignified death in order to support the government's wish to create a Danish model for a more dignified death in continuation of the tradition we have in Denmark for the care and treatment of palliative patients. The dialogue about a more dignified death will be a debate where one dilemma will often open the door to another. All perspectives are legitimate and important in an ethical debate like this.

The Committee for a more dignified death aims to create a debate with ethical considerations about the way Danes perceive dignity in the final phase of life. End-of-life dilemmas need to be brought to light to ensure a nuanced debate where all perspectives are heard. The Committee's work should also reflect that not all lives are the same, and there are different ways to leave this world. No one recipe for the end of life suits all people.

It is important that Danes and their views are included in the debate and that ethical perspectives are reflected. Different Danish values, such as self-determination, community and family, must be included in the debate. The Committee must make sure to get Danes to express their views and support Danes in forming their opinions.

In October 2023, the Danish Council on Ethics issued a statement on active assisted death. The Committee must include the Danish Council on Ethics's opinion in the ongoing debate on assisted end of life and use it to qualify and promote the upcoming public debate on the subject.

In its work, the Committee must take into account the legal and healthcare implications of possible initiatives in continuation of existing practices for the care and treatment of palliative patients.

The Committee's work will culminate in a reflection paper for the government on Danes' understanding of a dignified death in the different ways that life can end. The Committee's reflections must encompass Danes' attitudes to both natural death and assisted end of life in order to include Danes' opinions in the reflection paper. The Committee's work will help nuance the government's decision-making basis for a Danish model for a more dignified death.

Organisation

The Committee for a more dignified death is composed of 10 people appointed by the Minister of the Interior and Health. Kathrine Lilleør is appointed as chairperson of the Committee.

The Committee consists of both professionals and laypeople. A number of members are experts and practitioners who have knowledge of and practical experience within end of life in various fields. The Committee also consists of a number of lay people who have personal experience with end of life or who otherwise represent the Danish population.

When selecting Committee members, emphasis has been placed on a composition that ensures competences in the areas of healthcare, senior citizens and the spiritual, philosophical and/or social perspective. In its composition, it was also emphasised that the Committee should have insight into Danes' attitudes, e.g., as relatives or through other personal experience with the end of life.

Members will contribute with different perspectives on a more dignified death, ensuring a nuanced debate that reflects that not all lives are the same. The members must also contribute to public debate inputs and thereby support broad public debate in society.

The Committee is composed as follows:

- Members with end-of-life healthcare experience in the somatic or psychiatric field
- Members with experience in the field of senior citizens
- Members with end-of-life experience of a spiritual, philosophical or social nature
- Members representing the Danish population, e.g., relatives or others with personal experience with the end of life

The Committee's secretariat is provided by the Ministry of the Interior and Health of Denmark.

Process

The Committee must complete its work within one year. It is expected that the Committee will complete its work with a reflection paper on Danes' understanding of a dignified death in the different ways of ending life in the second half of 2024. The reflection paper will help nuance the government's decision-making basis for a Danish model for a more dignified death.

Appendix 2: Committee members

- Chairperson, Kathrine Lilleør – Parish pastor, PhD, Sankt Paul's Church in Copenhagen.
- Camilla Thorn Kristensen – Social and healthcare assistant in the home care in Thisted Municipality
- Janne Rothmar Herrmann – Professor, PhD in Health Care Law at the University of Copenhagen
- Janus Tarp – Head of Legal Affairs, Slagelse Municipality and Chairman of Danish Association of Accident Victims (UlykkesPatientForeningen) and Danish Polio Association (PolioForeningen)
- Kim Oskar Bakbo-Carlsen – authorised psychologist and head of department at VISP (Knowledge and Innovation Centre for Social Practice in Lemvig Municipality)
- Kirsten Jacobsen – Journalist, writer
- Lars Lior Ramsgaard – Nurse with special training in psychiatry at the emergency department at Aarhus University Hospital
- Thomas Søbirk Petersen – Professor, DPhil of Bioethics and Legal Philosophy at Roskilde University

Resigned members:

- Emma Helledie – Staff physician at the Palliative Care Unit, Department of Oncology at Aarhus University Hospital, President of the Danish Society for Palliative Medicine
- Jesper Grud Rasmussen – Nurse with subject area approval in the specialised palliative care field, Hospice Manager at Diakonissestiftelsen