

Assisted dying

A state of knowledge report

The Swedish National Council on Medical Ethics (Smer)

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Preface

One of the tasks of the Swedish National Council on Medical Ethics (Smer) is to stimulate societal debate on important issues of medical ethics. Smer also acts as the mediating authority between academia, citizens and policy makers. The Council has taken the initiative in creating this systematic review of assisted dying, with a focus on the “Oregon Model” practised in a number of American states, which has dominated Swedish debate in recent years.

The aim of the review is to create a knowledge base for the ongoing societal discussion on assisted dying. It discusses the central terms and definitions and describes the various models for legal assisted dying. A review is given of research and public statistics concerning assisted dying, where the focus is on the Oregon Model, but information from other countries is also presented. Following the description of the most common arguments for and against assisted dying, the report concludes with an analysis of the evidence to support the various factual arguments for and against assisted dying, based on the details that have emerged during the review process.

The report does not contain any stance on whether assisted dying should be allowed or not. Smer will continue to analyse the ethical questions on assisted dying.

As part of the work, the council has obtained opinions and facts from different organisations and people (see Appendix).

A working group comprising council members Kjell Asplund, Ingemar Engström and Elisabet Wennlund have worked to produce this report. Smer’s Head of Secretariat Lotta Eriksson (until July 2017) and acting Head of Secretariat Karin Mossler (as of August 2017) also participated in the work. The main author of the report was research officer Michael Lövtrup.

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In the present English translation, aspects that are specific to the Swedish context have been left out. The English text contains a few updates since the publication of the Swedish version, primarily concerning the jurisdictions where assisted dying is legal.

The translation was carried out by the translation agency Semantix, and has been revised by the secretariat of Smer.

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Summary

Why a report on assisted dying?

Since the 1970s, the Swedish debate on assisted dying has come in waves. Once again, we find ourselves in a period where there is a lively debate on the extent to which a person affected by a terminal illness should be able to obtain help to end their own life, and perhaps in this way avoid suffering at the end of their life. One reason for this increased momentum of the debate might be global developments, as more countries legalise assisted dying in some form.

As more countries legalise assisted dying and start to produce research and public statistics on the practise, there have been increased opportunities to assess the strength of several arguments raised by both advocates and opponents of assisted dying. This notwithstanding, the Swedish National Council on Medical Ethics (Smer) believes the debate has not developed as much as could be hoped for. Rather than contributing to deepening the debate, facts – or rather the assertion of facts – tend to become a weapon in the debate where each side presents their own “facts”, often without a source.

It is against this background that Smer has created this report. It provides a collated and updated picture of the existing research and statistics from countries and states where assisted dying is legal. The data is presented in relation to some of the most common factual arguments raised in the Swedish debate. The purpose is to assess the support for the arguments as a basis for continued debate on the matter.

In recent years, Swedish debate has focused on the assisted dying model used in a number of US states known as the Oregon Model. For this reason, the main emphasis of the report will be on information from Oregon and Washington, the two states that

have used the Oregon Model the longest. Information from the Benelux countries, Switzerland and other countries where assisted dying is permitted is presented in less detail, so as to provide a perspective on what has been established regarding the Oregon Model.

The report builds on approximately 100 academic articles and books, in addition to publications from government agencies and organisations in countries where any form of assisted dying is practised.

The report takes no stance on whether assisted dying should be allowed or not.

Definitions

This report defines assisted dying as *a procedure performed after an explicit request by a patient, where the intention is that the procedure will lead to the patient's death.*

Assisted dying that takes place when a person other than the patient conducts the decisive action resulting in the patient's death is referred to in the report as **euthanasia**. Assisted dying where the patient themselves conducts the decisive action is referred to as **self-administered assisted dying**.

There are two dominant models: The Oregon Model and the Benelux Model

Currently, approximately a dozen countries and federal states permit some form of legalised assisted dying. Among them, two models dominate – the Oregon Model and the Benelux Model.

The Oregon Model was introduced in Oregon in 1997 and is currently practised in a handful of American states. The model only permits self-administered assisted dying, and euthanasia is illegal. The determining criterion for access to assisted dying is that a person is terminally ill (has a maximum six months left to live). There are no conditions that state that the person must be experiencing severe suffering. The patient must be 18 years old and be capable, i.e. have the ability to make and communicate decisions about their own care.

The Benelux Model, used in Belgium, Luxembourg and the Netherlands, permits both euthanasia and self-administered assisted dying. The decisive criterion in order to be eligible for assisted dying is that the patient is suffering unbearably, and there is no alternative way of easing the suffering. The suffering may be physical or psychological. There is no requirement that the patient must be at the end of life. Both the Netherlands and Belgium permit assisted dying for children under the age of 18, provided they are deemed sufficiently mature to be able to safeguard their own interests. In the Benelux countries, a request for assisted dying can be made through an advance healthcare directive. This means that, in certain cases, patients who have lost their decision-making capacity may access assisted dying.

Countries in which legislation differs from these two models are Colombia, Canada and Switzerland. In Colombia and Canada, euthanasia is permitted but the patient must be nearing the end of their life. In Switzerland, only self-administered assisted dying is permitted, but there is no requirement for terminal illness to be present.¹

Different models have different consequences

The review of research studies and public statistics conducted in this report shows that it is not possible to provide an answer regarding the consequences of introducing assisted dying without specifying the model being discussed. In Belgium and the Netherlands, where euthanasia is permitted but there is no requirement for the patient to have a terminal illness, rates of assisted dying are ten times higher than in Oregon and Washington, where only self-administered assisted dying is permitted, and the patient must have a terminal illness. In Switzerland, where the only legal requirements are that the patient is capable and the person assisting the death does not stand to gain anything from the death, the proportion of women, the elderly and patients without a terminal illness is higher than in other countries where assisted dying is legal.

¹ In November 2017, the Australian state of Victoria ruled to introduce assisted dying as of June 2019 (see section 3.3.4.)

There are also differences in the motivation behind the patients' request for assisted dying. In Oregon and Washington, the dominating motivations are the fear of losing independence and quality of life at the end of life. Suffering without hope of improvement is the most common motivation in Belgium and the Netherlands.

Cancer is the dominant diagnosis, making up almost three-quarters of assisted dying cases. Patients with ALS and other neurodegenerative diseases also comprise a large group. In Oregon and Washington, assisted dying is not given to patients with psychiatric illness and dementia, yet in Belgium, the Netherlands and Switzerland, these groups make up one or two per cent of cases. In these countries, multimorbidity is also a reason for assisted dying.

In all the countries surveyed, assisted dying appears to be more common among people from higher socioeconomic backgrounds, the well-educated or people in affluent areas. In the majority of countries, the patients are somewhat younger than others with the same illnesses. With the exception of Switzerland, where women are in the majority, the rate of assisted dying is generally evenly distributed between women and men.

Two types of argument: value-based arguments and fact-based arguments

There are two distinct types of arguments in the assisted dying debate – value-based arguments and fact-based arguments. The value-based arguments deal with the principles or values it is believed should guide the stance on assisted dying. Autonomy is one example of a common value-based argument among advocates of assisted dying, suggesting that the right to determine our own life also includes our right to determine how it ends. Arguments on the sanctity of life, i.e. the argument that ending human life is always wrong, forms one common value-based argument from those opposing assisted dying.

Fact-based arguments address the alleged factual conditions believed to be relevant to the stance, for example the potential consequences of permitting assisted dying. One common fact-based argument in favour of assisted dying is that it would contribute to reduced suffering and counteract a perceived loss of dignity at the end of life. A common fact-based argument against assisted dying

is that it would reduce confidence in care, or result in a ‘slippery slope’, with assisted dying being given to ever-widening groups of patients.

A number of fact-based arguments are supported; others conflict with existing knowledge

By their very nature, it is difficult to use observations to confirm value-based arguments, whereas, in principle, fact-based arguments can be assessed using real-life observations. The increase in experiences from countries and states where assisted dying is permitted has extended the conditions for evaluating the support for the arguments. This could in turn promote a more knowledge-based debate on the topic.

The conclusions from the report regarding the support for some of the most common arguments for and against assisted dying are presented below. Unless otherwise stated, the conclusions primarily refer to the Oregon Model.

Arguments for assisted dying

Argument: Assisted dying can be a final way out when symptom management is insufficient

The information reviewed does not answer the question of whether there are situations where even the best palliative care cannot satisfactorily manage symptoms such as pain, anxiety, nausea and dyspnoea, or if the methods available in modern palliative care always provide suitable management of symptoms.

Nevertheless, the information available provides strong and unanimous support that severe symptoms are a less important reason for many of the patients in Oregon requesting assisted dying. At the same time, there is information to suggest that the Oregon Model is a less successful emergency measure for unbearable symptoms than the Benelux Model. This stems predominantly from the lack of advance healthcare directives, meaning that patients must be capable at the time of their request and may not be cognitively affected by powerful symptom management. Additionally, there is a

minimum waiting period of 15 days from the first application until the medication is prescribed, and the patient must be able to administer it themselves.

Argument: Assisted dying can counteract low quality of life and loss of dignity at the end of life

Unanimous information from the health authorities in Oregon and Washington and from research studies has shown that low quality of life, loss of dignity and independence, and the loss of control over bodily functions are important incentives behind patients requesting assisted dying and that these incentives often carry more weight than pain and other symptom-related reasons. Thus, in this respect there is relatively good support for the Oregon Model contributing positively to the final stages of life.

Argument: Assisted dying can give patients security and control in the final stage of their lives

There is some support that the feeling of security and control in an uncertain situation can be important to many of the patients who request assisted dying. Studies show that, for many patients in Oregon who request assisted dying, it is not the loss of control, loss of dignity or pain experienced at the time that are the reasons. Instead it is often a case of anticipating future problems. The fact that as many as one-third of patients do not use the medication also speaks for the importance of the security aspect.

Argument: Assisted dying can lead to fewer suicides among seriously ill elderly people

There have been attempts to study whether there has been any change in the development of suicide rates in the American states where self-administered assisted dying has been introduced. However, the results must be viewed with caution due to the difficulties in determining how the development would have progressed if assisted dying had not been introduced.

Arguments against assisted dying

Argument: Where there is good access to palliative care, there is no need for assisted dying

There is some support in research from Oregon to suggest that access to good palliative care can reduce the number of requests for assisted dying. At the same time, information indicates that for many patients, the experience of a dignified death is linked to needs that may not necessarily be met by palliative care – such as control over dying and maintaining independence. Nor has there been a decrease in requests for assisted dying from patients in Oregon and Washington in line with the increased availability of palliative care.

Argument: The question of assisted dying is discussed by healthy people, whereas those who are ill do not request it

In all the countries where assisted dying is permitted, there is an increased demand among patients. A majority of the patients requesting assisted dying are suffering from cancer. Neurodegenerative diseases are also common. Hence, the claim that no ill person requests assisted dying is contradicted by the information examined.

Argument: Palliative care will be neglected if assisted dying is permitted

In Oregon and Washington, the number of patients with access to palliative care at the time of their death is increasing and is at the same level as in other American states where self-administered assisted dying is not practised. All three Benelux countries are among the seven countries in Europe that invest the most in palliative care. Hence, information from Oregon and Washington, as well as the Benelux countries contradicts the idea that the development of palliative care would be impeded if assisted dying were to be legalised.

Argument: Assisted dying leads to a loss of confidence in the care system

There is no information regarding any impact of the legalisation of self-administered assisted dying on confidence in care in Oregon and Washington, neither among the general public nor specific groups – such as people with disabilities.

Argument: Medical assessments are uncertain

Information from Oregon and Washington support the claim that there is a level of uncertainty in the life expectancy prognosis, and that in certain cases where self-administered assisted dying is granted there is quite a considerable deviation between the prognosis and the outcome.

Argument: Patients opting for assisted dying do so because of depression

Research from Oregon and the Netherlands supports the claim that a number of patients who request assisted dying are suffering from depression. There is some support that this is more often the case than for other patients. At the same time, there are consistent research results from both Oregon and the Netherlands to show that many of the patients requesting assisted dying are not depressed – thus contradicting the idea that a request for assisted dying is an expression of depression. Many studies show that there is a stronger correlation between the demand for assisted dying and a feeling of hopelessness, regardless of whether the patient is depressed or not.

Argument: It is difficult to guarantee that the patient is capable

Regulations in Oregon and Washington state that patients who, as a result of depression or another psychiatric disorder have an impaired judgment, may not be granted assisted dying. It was not possible to find any information to highlight just how successfully this can be established. However, a decrease has been observed in

the number of patients undergoing psychiatric or psychological evaluation before their application for assisted dying is granted; a mere 4–5 per cent.

Argument: It is difficult to establish whether an application for assisted dying is voluntary and enduring

Information from Oregon shows that only one in nine patients considering assisted dying makes a formal request. This suggests that, for the majority of patients, going from considering assisted dying to the actual request is a relatively large step. As a rule, if the patient does actually make a request, it seems to be a considered and enduring decision.

No data has been found that clarify the steps taken in Oregon and Washington to guarantee that an application is voluntary. However, there is support that the desire not to be a burden on those around them is one of several reasons many patients give for requesting assisted dying.

Argument: The view of human beings in society could change if assisted dying is permitted

There is no evidence to support whether – and in such case how – people would change their views and understanding of everyone’s equal value in a country or federal state where assisted dying is legal.

Argument: If assisted dying is legalised, the practice will inevitably be extended to more patient groups (the slippery slope)

It has not been possible to find evidence to show the extent to which the legalisation of self-administered assisted dying in Oregon and Washington may have led to an increased frequency of assisted dying outside the legal framework. Nevertheless, regulations have been consistent. This speaks against the claim that a successive expansion of the criteria will be inevitable if assisted dying in any form is permitted.

Argument: Assisted dying will lead to “doctor shopping”

There is information to suggest that “doctor shopping” may occur in Oregon. This is when patients who are denied assisted dying by their regular physician keep searching until they find a physician willing to agree to assisted dying.

Argument: Assisted dying exposes vulnerable groups to specific risks

Information from Oregon and Washington shows that vulnerable groups are not over-represented among the patients to die from self-administered assisted dying, regarding sex, age, race, level of education or finances.

No information has been found relating to the extent to which patients with disabilities or chronic illnesses are over or under-represented.

Argument: Assisted dying can fail

Information from Oregon and Washington indicates that complications associated with self-administered assisted dying are uncommon. Vomiting or problems ingesting arise in approximately one in twenty cases. In one case out of 250, the patient woke up again after the procedure.

Argument: Assisted dying is a burden on healthcare staff

Studies from Oregon and the Netherlands support the statement that many physicians find providing euthanasia or self-administered assisted dying to be a deeply emotional undertaking associated with a strong sense of duty. However, only a few seem to regret the actions afterwards.

Information suggests that it is common for nurses and social workers in palliative care in Oregon to discuss self-administered assisted dying with patients. A number of them find these discussions uncomfortable.

Lessons for the continued debate

The review of research and statistics from countries and states where assisted dying is permitted shows that two conflicting opinions – both for and against assisted dying – both contain arguments supported by facts. In the analysis, we found three types of document for those fact-based arguments raised in the Swedish debate:

- a) Considerable arguments for and against self-administered assisted dying are supported by data from studies or public statistics. These arguments are relevant to the continued debate on assisted dying.
- b) As regards other arguments, the available data speaks against them. For the time being, these arguments should be excluded from the debate.
- c) For other remaining arguments, there is no data that speaks for or against the issue – the matter has simply not been researched. Such arguments need not necessarily be dismissed, although they should be raised with great caution and the lack of knowledge should be emphasised.

Smer wishes to emphasise that the evaluations made in the report only apply to how *sustainable* the arguments are, i.e. whether there is information to support them. Their *relevance* for the stance on assisted dying is another matter that is not addressed in this report. An ethical evaluation is needed in order to determine this. When reaching a definite stance on assisted dying, the different value-based arguments need to be factored in alongside the relevance of the various fact-based arguments.

How will Smer continue?

This report is Smer's contribution to the wider social debate on assisted dying. What then is the next step?

In a communication from 2008, Smer urged the government to appoint a commission of inquiry into how patients' self-determination could be increased at the end of life. The proposal did not result in any action from the government. As this compilation shows, the past decade has seen a significant increase in the

available information that has clarified several of the fact-based arguments raised in the debate. After compiling the opinions in the report, Smer will further assess how the council can contribute to the social debate on assisted dying.

1 Introduction

1.1 Why compile information on assisted dying?

The Swedish National Council on Medical Ethics (Smer) advises the Government and Parliament and other interested parties on matters of medical ethics. The council's mission also includes collecting and evaluating facts and being an agency for the exchange of information and opinion, stimulating societal debate on questions of medical ethics and having the role as an intermediary between science, general society and policy makers.

From the establishment of Smer in 1985, issues concerning self-determination and quality of life at the end of life have been an obvious part of the council's work. The more specific matter of assisted dying has also followed over the years, and has been addressed on several occasions, both internally at the council and as part of external activities such as debates, conferences and publications. On two occasions – 1996 and 2008 – Smer proposed that the government conduct an unconditional investigation examining whether assisted dying should be legalised. On both occasions, the ministers in charge – one a social democrat, the other from the centre-right – rejected the proposal.

Whilst interest on the subject is low among many politicians, opinion surveys suggest strong and increasing support for assisted dying among the general public. Nor has the societal debate regarding the question ever fallen silent; it has intensified over time. One contributing factor to its increased relevance is how more countries are legalising assisted dying. In 2016 alone, legislation on assisted dying was enacted in three jurisdictions: Canada, Colorado and California.

It is natural for Smer to take part in a debate that addresses a matter so central to medical ethics as self-determination and quali-

ty of life at the end of life. The council members bring together an array of experience and knowledge that can contribute to highlighting the entire complexity of the issue. Based on the low interest from most political parties, and how previous initiatives aimed at the decision makers have been received, Smer believes that the most productive work the council can undertake at present is in different ways to attempt to stimulate a deepened societal discussion on the matter.

In this context, Smer has identified a special need to provide a collected and updated picture of current knowledge and information about assisted dying. Despite the council believing the matter of assisted dying to be predominantly an ethical question, as it balances different intrinsic values and goals against each other, facts are often necessary so as to be able to determine the extent to which these values/goals will benefit or suffer from the legalisation of assisted dying following any of the possible models.

Here, conditions have changed radically since the inception of the assisted dying debate in Sweden in the 1970s. Back then, there were few experiences of openly practised assisted dying. Consequently, many of the facts stated were hypothetical; if assisted dying were to be introduced, it would either lead to these positive or negative consequences. Today, the situation is completely different. There are several jurisdictions (countries and federal states) where assisted dying has been practised for decades. In line with the increase in experience from these countries, there is also a greater tendency for debaters to look to the development in these countries to support their arguments for or against assisted dying.

Nevertheless, the debate has not developed to the extent that could have been expected, or at least hoped for. Rather than deepening the debate, facts – or rather the assertion of facts – tend to become a weapon. There is much sweeping and contradictory information about the development in countries and states where assisted dying is permitted – information that is often presented without any source. The potential that factual knowledge could provide – i.e. the contribution to more informed and nuanced opinions – is yet to be realised. Instead, each side has their own “facts” that reinforce the polarisation.

It is against this background that Smer chose to create this report. The purpose is to conduct a broad review of research and

public statistics on the implementation of assisted dying that can be found in the jurisdictions where any form of assisted dying is legal, and to place the information collected from the inventory in relation to some of the most common arguments in the debate on assisted dying (the arguments have been taken from the Swedish debate, but to a great extent can be found in the debate in other countries). The aim is twofold. The first aim is to assess the available support for the arguments as a basis for continued debate; the second, just as important, is to identify gaps in knowledge. As is evident in this report, the answer to the question of what will happen if assisted dying is introduced is in many ways that we do not know.

1.2 Limitations and methods

Certain limitations were necessary, as the council's resources could not cover an equally comprehensive review of all research on assisted dying from around the world. And so, it has been natural to focus on the model given greatest attention in the recent debate in Sweden, namely the "Oregon Model", introduced in the American federal state of Oregon in 1997, which has later been introduced to other American states.

The report builds on approximately 100 academic articles and books, in addition to a large collection of statistics and other materials from government agencies and organisations in countries where assisted dying is implemented in any form. The reviewed research on the Oregon Model was found via a conventional literature search, whilst statistics that supplement the academic material are from public sources. The council has chosen to exclude information about single patients, whether this was included in academic articles or other sources. The reasons for this are, in part, because the information may be difficult to verify, and also that it is unclear just how representative the information is to the practices described.

The review of arguments for and against assisted dying was conducted by the working group and the main author. It is based on the debate that followed after Smer submitted a proposal to the government in 2008 to examine legalisation on assisted dying.

1.3 Structure of the report

The report begins with a presentation of terms and definitions. To provide background, the report examines legislation in the different jurisdictions where assisted dying of any kind is permitted.

A review of research and other data from these jurisdictions then follows, with emphasis on the Oregon Model.

The two final chapters provide a review of some of the most common arguments in the Swedish debate. This is followed by a discussion of the support available for the different arguments based on the information presented, also with emphasis on the Oregon Model.

2 Terms and definitions

This report uses **assisted dying** as an overarching term for procedures performed after an explicit request from a capable patient, where the intention is that the procedure will lead to the patient’s death. Assisted dying that takes place when a person other than the patient conducts the decisive action resulting in the patient’s death is termed **euthanasia**. Assisted dying where the patient conducts the decisive action themselves is referred to as **self-administered assisted dying**.

2.1 Terms used in the report

The power of language over thought can be considerable, and the terms used in the debate on assisted dying are not without significance. For example, the support for assisted dying recorded in opinion polls prior to the referendum in Oregon in 1994 is said to have declined by 10 and 12 per cent when the words “suicide” or “euthanasia” were used instead of “dying with dignity”.² Understanding the power of language is undoubtedly part of the reason that organisations in favour of assisted dying readily refer to it as the right to a “death with dignity”.³ Synonyms for assisted dying that use the term dignity are seldom accepted by opponents of assisted dying. Many of them believe that a death with dignity is not compatible with assisted dying, or that death with dignity is always possible without assisted dying.

² Campbell and Cox 2010.

³ See deathwithdignity.org. Interestingly, in Oregon, where assisted dying is permitted if the patient carries out the act themselves, legislation neither mentions “assisted suicide” nor “assisted dying”; instead, it states how the patient can “end his or her life in a humane and dignified manner”, see Oregon Health Authority (n. d. [a]).

One term that is often called into question in both the Swedish and international debate is physician-assisted suicide. For example, several American organisations such as the American Academy of Hospice and Palliative Medicine, American College of Legal Medicine and the American Public Health Association have recommended that the term suicide not be used in connection with assisted dying.⁴ One reason for objecting the use of the term suicide is that it can conjure thoughts of (perhaps ill-considered) actions based on desperation, often influenced by psychiatric disorders. These people without terminal illnesses still have the chance for a good life but lack the will to live. However, the situation for terminally ill patients is said to be the opposite – they want to live, but there is no hope and so they wish to avoid the pain of their final hours or avoid an undignified death. Others object and say that (assisted) suicide is the correct term as it “tells it like it is”.

As far as possible, Smer wishes to avoid the focus being placed on the choice of words instead of the factual issue, and in this report uses **assisted dying** as an overarching term for the procedures performed to end a terminally ill patient’s life at their request. Assisted dying that takes place when a person other than the patient conducts the decisive action that resulting in the patient’s death is referred to using the internationally recognised term **euthanasia**. Assisted dying where the patient conducts the decisive action themselves is referred to as **self-administered assisted dying**.

2.2 Some important definitions

Before we proceed to the definition of assisted dying, some other central terms require clarification. Definitions marked with (*) are translations of terms from the Swedish National Board of Health and Welfare term bank.

⁴ <https://www.deathwithdignity.org/terminology/>

Capable

One condition for a patient to be able to make independent decisions about their care and treatment is that they are capable. Being capable means that the patient has the ability to understand sufficient information and foresee the consequences of their decision. Occasionally, the expressions *capable of decision-making* or *decision-making capacity* are used.

Advance healthcare directive

A decision made by a capable person regarding their desired treatment or the treatment from which they wish to abstain in a future care situation when they are no longer capable. Advance healthcare directives are sometimes referred to as living wills.

*Life support**

Treatment given in life-threatening situations to preserve a patient's life.

*Palliative sedation**

Sedation administered to a patient at the end of life via intermittent or continual supply of sedatives and tranquillising medication, at a dose sufficient to lead to such a loss of awareness that the patient is no longer conscious of their severe symptoms.

*Palliative care**

Health and medical care that aims to reduce suffering and improve the quality of life for patients with progressive, terminal illness or injury, which takes physical, psychological, social and existential needs into account, in addition to providing organised support to the patient's relatives.

Terminal illness

An illness that cannot be cured, where death is inevitable and can be expected in the near future.

A term closely related to terminal illness and often arising when discussing assisted dying is “end of life”. For example, many people support assisted dying for patients at the end of life, but not in other situations. Additionally, the option of providing assisted dying is often discussed as one of several “end-of-life decisions”. As with terminal illness, a condition for being at the end of life is that death is unavoidable due to the patient’s condition, and is expected to occur in the relatively near future. Considering how common the term is, even in this report, a more concise definition would be preferable, (should the patient have weeks to live, or months – even years?). We believe it to be impossible to provide such definition, especially as the term is seldom defined in the literature referred to in the report. As a rule, the term can be said to encompass more than just the final days or weeks.

2.3 Definition of assisted dying

The definition of assisted dying used in this report is based on four distinctions that can be made on matters of healthcare measures that can bring about a patient’s death:⁵

Type of measure. Cases where a procedure is performed versus cases where a procedure is abstained from or discontinued.

Request. Cases where the measure is based on a request from a capable patient, versus cases where the measure is based on a medical evaluation.

Intention. Cases where death is deliberate (either as a goal in itself or more often, as a means to attain a specific goal) versus cases

⁵ The distinctions have been somewhat modified from those in the definition suggested by the Canadian philosopher Wayne Sumner. See Sumner 2011.

where death is a foreseen, but not an intended side-effect of efforts to reach a different goal or purpose.

Agency. Cases where a procedure is performed by a physician, versus cases where the means for the procedure are provided by the physician but employed by the patient themselves.

With the aid of the first three definitions, assisted dying can be defined *as a procedure performed after an explicit request by a patient, where the intention is that the procedure will lead to the patient's death.*⁶

In the Benelux countries, the procedures to hasten a patient's death can be stipulated in a person's advance healthcare directive. If this is to be included in the term "assisted dying", the request criterion must be interpreted such that previous requests also meet the criteria, if they are still considered relevant at the time assisted dying is administered.

The fourth distinction, "agency" is used to distinguish between the two forms of assisted dying available. If a physician performs the procedure, it is a case of euthanasia. If a physician prescribes medication that the patient will take themselves, it is a case of self-administered assisted dying.

⁶ Occasionally, definitions of assisted dying also include the condition that the patient is seriously ill. For all legally regulated assisted dying, a patient must meet certain medical requirements. As a rule, the patient must be suffering from a terminal (incurable and fatal) illness and/or be experiencing unbearable suffering. However, this should be seen as one of several conditions for the practical application, and not part of the definition.

3 Models for legalised assisted dying

Approximately a dozen countries and federal states currently permit some form of legalised assisted dying. Two models dominate – the Oregon Model and the Benelux Model.

The Oregon Model is currently practised in a number of American states. The model only permits self-administered assisted dying, whereas euthanasia is illegal. The determining criterion for access to assisted dying is that a person has a maximum of six months left to live. However, there are no conditions that state that the person must be experiencing severe suffering.

The Benelux Model used in Belgium, Luxembourg and the Netherlands permits both euthanasia and self-administered assisted dying. The decisive factor to be allowed access to assisted dying is that the patient is suffering unbearably, and that there is no other alternative to ease the suffering. Suffering may be physical or psychological. There is no requirement that the patient be at the end of their life.

Switzerland, Colombia and Canada go against this pattern. Euthanasia is forbidden in Switzerland, whereas self-administered assisted dying has become accepted in situations where death is not inevitable. In Colombia and Canada, both euthanasia and self-administered assisted dying are permitted, but the patient must have a terminal illness.

3.1 The Oregon Model

3.1.1 Oregon

In Oregon, the so-called Death with Dignity Act permits self-administered assisted dying but not euthanasia. The law was introduced after a citizen's initiative and came into force in 1998. It got support from a referendum in 1994, then was stopped by the courts, and once more supported in a new referendum in 1997. In 2001, the Bush administration attempted to block the law through a directive which would leave physicians prescribing medication for self-administered assisted dying at risk of losing their right to prescribe. Eventually, the matter was taken to the US Supreme Court, who backed the legislation in a ruling from 2006.⁷

The law enables physicians to prescribe a lethal dose of medication to a patient registered in the state of Oregon, over the age of 18 years, capable⁸ and suffering from a fatal illness that, according to a "reasonable medical judgment" is expected to result in death within six months.⁹ The limit applies to cases where no treatment will be given to inhibit the progression of the illness.¹⁰

The first step in the process is that the patient orally requests to be allowed to die. The patient's physician must then ensure that the patient meets the requirements to receive assisted dying, and that their request is voluntary. The patient's physician must ensure that the patient is informed about:

1. His or her medical diagnosis
2. His or her prognosis
3. The potential risks associated with taking the medication to be prescribed
4. The probable result of taking the medication to be prescribed

⁷ The judgment can be read via <https://www.law.cornell.edu/supct/html/04-623.ZS.html> (retrieved 2017, May 01)

⁸ "has the ability to make and communicate health care decisions".

⁹ The legislation, annual reports and other materials about self-administered assisted dying in Oregon can be downloaded from the Health Authority website. Oregon Health Authority (n.d.[a]).

¹⁰ After conversation with Linda Ganzini 2017, March 16.

5. The feasible alternatives, including, but not limited to, comfort care, hospice care and pain control.

The physician must also inform the patient of their right to withdraw their request at any time and in any manner. The physician must also recommend that the patient notifies their next of kin about their decision and counsel the patient about the importance of another person being present when the medication is consumed.

Both the medical requirements and that the patient is capable and is acting voluntarily must be certified by an additional physician (called the “consulting physician”). If either of the physicians believes that the patient may be suffering from a psychiatric disorder that affects their judgement, a psychiatrist or psychologist must be called upon. No prescription for medication to be used in self-administered assisted dying may be issued until it has been established that the patient’s judgment is not impaired as a result of “psychological or psychiatric disorder or depression”.

Once it has been ascertained that the patient meets the requirements and the patient has been duly informed, a written request for self-administered assisted dying can be submitted by the patient. The written request must be witnessed by two people who can certify the person is capable and is acting voluntarily and not under coercion. At least one of the witnesses must not be a close relative, be set to inherit anything from the patient or have any link to the institution where the patient lives or is receiving treatment. The patient’s physician may not be a witness.

The prescription of medication may not be issued until a minimum of 48 hours have passed since the written request was submitted. Before the patient’s physician prescribes the medication, the patient must make an additional oral request. At this point, at least 15 days must have passed since the first oral request. In connection with the prescription, the physician must once more establish that the decision is informed and offer the patient an opportunity to withdraw their request.

The law stipulates that no healthcare employee or provider is obligated to participate in the provision of self-administered assisted dying. Pharmacists have the right to refuse to dispense the medication for self-administered assisted dying. Healthcare providers may deny their staff the right to participate in self-administered

assisted dying on their premises. However, providers may not prevent one of their physicians from discussing the legal possibilities with the patient, or from participating in providing self-administered assisted dying outside of the provider's organisation. Healthcare providers must also provide the necessary medical records to another provider who intends to participate in providing self-administered assisted dying.

Coercing, or in any other way improperly influencing a patient to choose to request assisted dying, is regarded as a serious crime, as is forging or changing a written request for self-administered assisted dying.

According to the Death with Dignity Act, no will and testament, contract, insurance policy or other legal claim may presuppose that a person requests or abstains from assisted dying.

Wishes expressed by the patient, physician's assessments and the offer to withdraw the request must be documented in the patient's medical records. The information must be sent to the state health authority with seven days of the patient's physician prescribing the medication for self-administered assisted dying. The person dispensing the medication must also report to the authority. Regardless of the cause of death, within ten days of the patient's death the physician must submit a form outlining the circumstances of the death, and the patient's grounds for requesting self-administered assisted dying.¹¹ If the health authority believes that any aspect of the regulations has not been followed, this is reported to the state's licencing body, the Oregon Medical Board. Each year, the health authority compiles a report of the law's implementation based on the information reported.

3.1.2 Other American states that have implemented the Oregon Model

Following Oregon's implementation of the Death with Dignity Act, an additional six American states have introduced self-administered assisted dying: Washington (2009), Vermont (2013), Colorado (2016), California (2016), Washington D.C. (2017) and

¹¹ Oregon Health Authority (n.d.[b]).

Hawaii (2018). To a great extent, the legislation in these states is the same as in Oregon, even though there are some minor differences. In Vermont for example, at least two people without links to the patient must act as witnesses. In California, the patient must fill in a final attestation form no later than 48 hours prior to the medication being taken to confirm that they have received all the information.¹²

3.1.3 Montana

Unlike other American states where self-administered assisted dying is legal, Montana has not introduced any new legislation. Instead, self-administered assisted dying has been decriminalised (i.e. is not punishable by law) following a legal process where a terminally ill patient and his physicians turned to the courts to be awarded the right to end his life via self-administered assisted dying. In 2008, a judge in the first instance ruled in that a capable patient with a terminal illness has the right to end their own life. This follows from the state's constitutional rights of individual privacy and human dignity. Physicians assisting a patient in such a case are not guilty of a crime. In 2009, the state's supreme court maintained that self-administered assisted dying for the terminally ill is not illegal. Attempts have since been made to either forbid self-administered assisted dying or regulate the right to self-administered assisted dying through specific legislation, as in Oregon and other states. None of these proposals have been adopted.

3.2 The Benelux Model

3.2.1 The Netherlands

In 1973, public debate on assisted dying gained momentum after a physician was prosecuted for having performed euthanasia on her mother who had cancer. The physician was found guilty of murder, but received a short suspended sentence.¹³ Following several simi-

¹² Source: www.deathwithdignity.org (retrieved 2017, October 09).

¹³ Rietjens et al. 2009.

lar legal trials, a practice developed where prosecutors abstained from prosecuting physicians who provided their patients with assisted dying, on the condition that specific criteria were met. These included that the patient had made repeated requests, was capable and was suffering severely in a way that could not be relieved by other means.

Assisted dying continued to be illegal, and there was no guarantee of being exempt from prosecution. This led to a lack of reliable figures about the frequency of assisted dying, as the fear of legal repercussions led to physicians not registering every case.

In 1990, there was a formal declaration that a physician who met the set criteria would not be prosecuted, and in 2002, legislation was passed to regulate self-administered assisted dying and euthanasia. It was also written into the Dutch Penal Code that assisted dying does not constitute a crime.¹⁴

The law states that only physicians can provide assisted dying without being criminally responsible. For a physician to have the right – but not the obligation – to administer assisted dying, they must meet the due care criteria. These state that the physician shall:

1. Be satisfied that the patient's request is voluntary and well-considered
2. Be satisfied that the patient's suffering is unbearable, with no prospect of improvement
3. Have informed the patient about their situation and prognosis
4. Have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation
5. have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in 1 to 4 have been fulfilled
6. Have exercised due medical care and attention in terminating the patient's life or assisting in his suicide.¹⁵

¹⁴ Rietjens et al. 2009

¹⁵ An English translation of the legislation is available in the Regional Euthanasia Review Committee's annual report for 2015; see Regional Euthanasia Review Committee 2016.

In the Netherlands, there is no requirement that the request be in writing. It is possible to request assisted dying from the age of twelve, provided that the patient is sufficiently mature to be able to safeguard their own interests. Parental consent is required for patients under 16 years old. When the patient has reached the age of 16, but before they turn 18, their parents must participate in the decision-making process, although they may not say no.

Each case of assisted dying must be reported to the local municipal pathologist, who in turn submits a report to one of five regional euthanasia review committees. If the municipal pathologist or review committee believe that the legal requirements have not been met, the prosecutor shall be informed. A breach of the regulations can lead to up to twelve years' imprisonment. Each year, the committees must compile a joint report to the Dutch Ministry of Health, Welfare and Sport regarding the implementation of assisted dying.

According to guidelines from the regional euthanasia review committees, the question of what constitutes a suitable alternative does not need to be assessed by the physician alone; the patient's perspective can also be taken into consideration. The question of suffering must also be assessed from the patient's perspective. Nevertheless, it must be "palpable" to the physician that the patient's suffering is unbearable.¹⁶

Euthanasia (self-administered assisted dying is not applicable in these cases) for those with dementia and other patients who cannot express their wishes is permitted if there is a written advance healthcare directive and if the other regulations are followed. According to the regional review committees, assisted dying may also be administered to a patient who has been affected by a reduced level of consciousness if this takes place just before the procedure has been planned and the suffering remains.¹⁷

In addition to the legislation, there are a few significant precedents that apply to interpretation of the criteria for due care. The 1994 Chabot Case saw the Supreme Court of the Netherlands establish that psychological suffering may be so severe that it can meet the legal requirements, although physicians must be particu-

¹⁶ Regional Euthanasia Review Committees 2015.

¹⁷ Regional Euthanasia Review Committees 2015.

larly cautious in the case of patients whose suffering is primarily psychological. Above all, it must be guaranteed that the patient's judgement is not influenced by the illness.¹⁸ Following recommendations from the regional euthanasia review committees, two independent physicians must be consulted in such cases, of which one is a psychiatrist. A key issue is determining that there is no hope of improvement. If the patient refuses suitable treatment methods, the condition cannot be considered hopeless.

In the Brongersma Case from 2002, the Supreme Court of the Netherlands made it clear that suffering must be based on a medical condition – treating someone who is tired of life or whose suffering is of a more existential nature is not part of the physicians' task.¹⁹ On the other hand, there is no requirement for the condition to be serious or life-threatening. According to the review committees, age-related multimorbidity can cause unbearable suffering without hope for improvement.

In the autumn of 2016, the Dutch ministers of health and justice announced that they wanted to see a new law that provides the possibility of self-administered assisted dying for the elderly who are not suffering unbearably due to a medical condition, but who are “finished with life”.²⁰ The Royal Dutch Medical Association is against such legislation on both practical and moral grounds, believing it would risk undermining the current rigorous assisted dying practice and lead to a stigmatisation of ageing.²¹

3.2.2 Belgium

In 2002, the same year that the Netherlands legalised assisted dying, so did Belgium. Unlike the Netherlands, Belgium had no tradition of openly practised assisted dying (however, the secret practice of euthanasia as well as ending of life without an explicit request from the patient was relatively common²²). Since the Belgian Advisory Committee on Bioethics issued two statements in 1997

¹⁸ Griffith 1995.

¹⁹ Sheldon 2003. See also KNMG 2011.

²⁰ Government of the Netherlands 2016.

²¹ KNMG 2017a.

²² Deliens et al. 2000.

and 1999 highlighting legalisation on assisted dying as one of several possible options, the new law was adopted after a relatively short political process.²³

Belgian regulations are rather similar to those in the Netherlands but are more exhaustive.²⁴ The basic requirement is that both the physician and patient must establish that suffering is unbearable and cannot be relieved in any other way. The suffering must originate from an incurable medical condition (illness or accident). The law is explicit, stating that the suffering may be either physical or psychological. Belgian regulations also emphasise that the request to receive assisted dying may not just be voluntary – the patient must also be capable (“legally competent”). Unlike in the Netherlands, an oral request is not sufficient; the application must be submitted in writing. The physician must follow the patient over a “reasonable period of time” in order to assure themselves that the request to die is persistent and the suffering lasting. In cases where the patient is not expected to die within the near future, two independent physicians must be consulted, of whom one must be a psychiatrist or a specialist in the patient’s condition. In these cases, a minimum period of one month must pass between the request and the implementation.

Another difference compared to the Netherlands is that Belgian regulations only mentions “intentionally terminating life by someone other than the person concerned”, which might be interpreted as only permitting euthanasia. The grounds for the limitation are unclear, but one explanation may be that, in Belgium, assisting suicide is not punishable by law.²⁵ The national review committee that monitors the application of the law (see below), has, however, stated that it believes that “the way in which euthanasia is to be administered” is not laid down in the law, and that therefore self-administered assisted dying is permitted.

²³ Meulenbergs and Schotsmans 2002.

²⁴ The law is available in both Flemish and French from the Federal Public Service Health, Food Chain Safety and Environment website: http://www.health.belgium.be/sites/default/files/uploads/fields/fpshealth_theme_file/loi20020528mb_frn.pdf (retrieved 2017, May 01). An English translation was published in the journal *Ethical perspectives*: <http://www.ethical-perspectives.be/viewpic.php?LAN=E&TABLE=EP&ID=59> (retrieved 2017, May 02).

²⁵ Nys 2003.

Conditions for advance healthcare directives are somewhat stricter in Belgian law. The directive may be a maximum of five years old and will only be taken into consideration if the patient is in a state of irreversible unconsciousness. When the law was implemented, only those who had reached legal age could be considered for assisted dying. In 2014, this restriction was lifted, and Belgium became the first country to allow children of all ages to be granted assisted dying, on condition that the child is believed to be able to rationally express their wish to die. In these instances, the child must be terminally ill. The parents must also provide their consent.

Each case of euthanasia must be reported to a national commission, who will assess whether regulations have been followed. Every two years, the commission compiles a statistical report on assisted dying and evaluates the law.

No physician is forced to agree to an application for euthanasia, although those who do not wish to conduct the procedure must inform the patient as soon as possible. Should the patient request this, the physician must forward the patient's data to another physician prepared to administer assisted dying.

3.2.3 Luxembourg

In 2009, a law was adopted permitting assisted dying in Luxembourg. The law is similar to the Belgian euthanasia law, but also addresses self-administered assisted dying. In contrast to the other two Benelux countries, Luxembourg stipulates that the patient must be of legal age.²⁶

When the law was passed by the Luxembourg Parliament, it was refused royal ascent. This triggered a constitutional crisis, which in turn led to parliament removing any remaining formal powers from the Grand Duke of Luxembourg.

²⁶ The law can be obtained from the Grand Duchy of Luxembourg online publication, Journal officiel du Grand-Duché de Luxembourg: <http://legilux.public.lu/eli/etat/leg/loi/2009/03/16/n2/jo> (retrieved 2017, May 02).

3.3 Other models

3.3.1 Switzerland

According to article 115 of the Swiss Criminal Code, no other person may assist another person's suicide "for selfish motives". In case law, this has been interpreted such that anyone – not just physicians – can assist a suicide, as long as they will not benefit. However, it is explicitly forbidden that any other person may perform the act that results in death, even if this takes place with the consent of the individual, and without any selfish motive. In other words, euthanasia is forbidden.

Organised forms of self-administered assisted dying began being practised at the end of the 1980s via the Exit organisation. In addition to Exit, the most important assisted dying organisations are Exit ADMD – a sister organisation of Exit aimed at the Romansch-speaking areas of Switzerland – and Dignitas. In contrast with the other two organisations, Dignitas offers assisted dying for foreign citizens. A person must be a member of one of the assisted dying organisations to be granted access to self-administered assisted dying. Exit and Exit ADMD have approximately 130,000 members, approximately 1,5 per cent of Switzerland's residents. Dignitas has approximately 7,000 members.²⁷

All these organisations presume that the person is an adult²⁸ and capable to be able to access self-administered assisted dying. As for the medical requirements, a person must:

1. be suffering a terminal or incurable illness, or
2. be experiencing unbearable symptoms or,
3. have an unbearable disability.^{29,30,31}

If the criteria are met, the patient's physician, or a physician cooperating with the assisted dying organisations, will prescribe a lethal dose of medication which the patient will then take. Case law states

²⁷ Bosshard 2017, p. 30.

²⁸ Exit: 18 years old, Dignitas: "adult", Exit ADMD: 20 years old.

²⁹ Exit (n.d.).

³⁰ Dignitas (n.d.).

³¹ Exit ADMD (n.d.).

that an intravenous drip may be used if the patient is unable to swallow, on condition that the patient adjusts the flow themselves.³²

When the practice began in Switzerland, it was unclear whether the physicians who worked with the assisted dying organisations and who prescribed the necessary medication could do so without the risk of losing their licence. In a judgment from 1999, there was a ruling that physicians can participate in self-administered assisted dying without contravening the applicable regulations, providing certain conditions are met. One such condition is that the physician meets the patient and confirms that they are capable.³³ This was confirmed in a judgment from the federal supreme court of justice in 2006, in which it was stipulated that psychological suffering can also be unbearable, and mental illness does not necessarily mean a decrease in decision-making capacity. Consequently, patients with mental illness can also request self-administered assisted dying. Nevertheless, a statement is required from a psychiatrist to confirm that the will to die is not an expression of a treatable psychiatric disorder but is the considered and lasting decision of a prudent person.³⁴

In this respect, the law is more tolerant than the Swiss Academy of Medical Sciences (SAMS). For a long time, this organisation has believed that participating in self-administered assisted dying is not a part of a physician's tasks, but it should be respected as an act of conscience. In 2004, SAMS approved non-binding ethical regulations that state that a patient must be terminally ill, must have been offered alternative treatment, must be capable, and must have reached the decision without external pressure. The final two conditions must be certified by a person other than their physician. The death shall always be reported to the authorities as an unnatural death.³⁵

³² Bosshard 2017, p. 33.

³³ Bosshard 2017, p. 31.

³⁴ Bosshard 2017, p. 32.

³⁵ SAMS 2004. There is criticism of the limitation of terminal illness, and an overhaul of the guidelines has been ongoing since 2012, see SAMS (n.d.). A survey conducted in connection with the overhaul has, however, shown that there is extensive support from physicians for keeping the limitation to terminal illness, see Brauer, Bolliger and Strub 2015. Nonetheless, in the new guidelines adopted in March 2018, the requirement for terminal illness was withdrawn, see SAMS 2018.

The self-administered assisted dying procedure is forbidden at Swiss hospitals, with few exceptions. Regulations vary for nursing homes, but staff are often prohibited from participating.³⁶

There have been attempts in Switzerland to legally limit the possibilities of self-administered assisted dying, although they have failed, as have proposals to introduce specific legislative regulations for assisted dying, as in Oregon or the Benelux countries.

3.3.2 Canada

Previously, it was completely illegal to assist suicide in Canada. But in 2011, a patient with ALS challenged the extent to which the ban on assisting suicide complied with the constitutional right to life, freedom and security, if a person with a serious and incurable disease wishing to end their suffering is forced to do this earlier than would be the case if assisted dying were available.

The case was carried all the way to the supreme court of Canada. The crux was whether it was possible to protect vulnerable groups from abuse. In a unanimous verdict in February 2015, the court decided that it was possible if assisted dying were limited to capable adults who had provided clear consent and who were suffering from a serious, incurable medical condition that would lead to lasting and unbearable suffering.³⁷ However, the court did not decide to abolish the ban with immediate effect; instead, it gave the government twelve months to create a legal framework for self-administered assisted dying.

After the designated period was extended by a further four months, in June 2016, a new law was passed permitting a physician or nurse practitioner to administer assisted dying as both self-administered assisted dying or euthanasia.³⁸ The requirements stat-

³⁶ Bosshard 2017, p. 33.

³⁷ It was the need to protect vulnerable people from pressure that led to the same court ruling the opposite way in 1993. One difference highlighted in the new judgment is that evidence is now available from other countries with assisted dying that does not suggest any 'slippery slope' in this respect. The entire judgment can be read on <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do> (retrieved 2017, June 05).

³⁸ The law can be accessed from the website of the Canadian parliament: <http://www.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1&DocId=8384014> (retrieved 06/05/2017). A summary of the law can be read on <http://eol.law.dal.ca/> (retrieved 2017, May 06).

ed that the patient be covered by the Canadian healthcare insurance system, be 18 years old or more, be capable, and have submitted a voluntary request without being subjected to external pressure. The patient must have a grievous and irremediable medical condition, meaning being at an advanced stage of an illness or disability that cannot be cured or treated and that leads to enduring physical or psychological suffering. Suffering must be intolerable to the patient, and impossible to alleviate under conditions acceptable to the patient. The death must be reasonably foreseeable, but a prognosis as to the specific length of time remaining is not necessary. The patient must have been informed about the alternatives available to alleviate the suffering, including palliative care.

A written request for assisted dying, witnessed by two independent persons must have been submitted. To meet a person's wish for assisted dying, the physician or nurse must be satisfied that the above criteria have been met. This must also be certified by a second physician or nurse.

The patient must also have been informed of their right to withdraw their request at any time. In regular cases, a minimum of ten days from submitting the written request must elapse before assisted dying is administered, although a shorter period is possible if the patient risks dying or losing their ability to provide their consent. In conjunction with the administration of assisted dying, the physician or nurse must once more inform the patient of their right to withdraw, and ascertain that the patient consents.

3.3.3 Colombia

In a judgment from 1997, the Constitutional Court of Colombia ruled that it is not punishable for a physician to end the life upon request of a terminally ill patient who is suffering extensively and does not wish to extend their suffering. The court requested elected representatives to draft suitable regulations.³⁹ Yet it would take until 2015 until the Ministry of Health and Social Protection decided on guidelines after the request from the Constitutional Court.

³⁹ Gaviria Díaz 1997.

To be granted assisted dying in Colombia, a patient must be of legal age, have clearly expressed their wishes and be terminally ill.⁴⁰ Following the decision, all caregivers are obliged to guarantee access to assisted dying, but individual physicians may refuse. Before assisted dying is administered, there must be verification that the patient has access to palliative care. Each case must be approved by a committee comprising a physician, lawyer, and a psychiatrist or psychologist. The committee has 10 days to establish whether the requirements have been met. Upon approval, the decision must be implemented within 15 days.⁴¹

In 2018 the Ministry of Health and Social Protection issued a resolution permitting euthanasia also for children from seven years.⁴²

3.3.4 Victoria (Australia)

In November 2017, the Parliament of the federal state of Victoria in Australia decided to legalise assisted dying for terminally ill patients suffering in a way that cannot be alleviated in a manner acceptable to the patient. The patient must have lived in the state for a minimum of twelve months, and have repeated their request three times, one of which in writing. Time is normally limited to a maximum of six months' expected survival, although for patients with neurodegenerative diseases such as ALS and multiple sclerosis the limit is twelve months. In regular cases, assisted dying must be self-administered assisted dying. However, unlike in Oregon or other American states, euthanasia may be permitted in special cases if the patient is physically unable to administer the medication themselves. The law will enter into force in June 2019.⁴³

⁴⁰ The law does not mention either euthanasia or self-administered assisted dying, instead it states "dying with dignity". Secondary literature suggests that both forms of assisted dying are included, see for example Emanuel et al. 2016.

⁴¹ Minsalud 2015.

⁴² Triviño 2018.

⁴³ The law can be accessed from the official Victorian Government website: [http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e92000e23be/B320E209775D253CCA2581ED00114C60/\\$FILE/17-061aa%20authorised.pdf](http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e92000e23be/B320E209775D253CCA2581ED00114C60/$FILE/17-061aa%20authorised.pdf) (retrieved 2018, September 14).

4 Self-administered assisted dying following the Oregon Model – what do we know?

This chapter aims to provide further information about the Oregon Model of assisted dying, which in recent years has been the model discussed most in the Swedish debate. The purpose is to provide a comprehensive picture of the existing knowledge of the model. The aim is to examine the arguments for and against self-administered assisted dying that have been raised in Swedish debate.

To provide a perspective of the knowledge surrounding the Oregon Model, short summaries of relevant literature concerning other models are also presented – mostly the Benelux model, that also includes euthanasia, and the self-administered assisted dying model implemented in Switzerland.

4.1 Sources

Legislation in the American states that use the Oregon Model demands that the physician prescribing the medication for self-administered assisted dying submits information from medical records to the state health authorities. Once the patient has died, the attending physician must submit supplementary information to the authority. This information forms the basis of annual reports published by the authorities, which contain a range of statistics regarding the application of the model.⁴⁴ In this chapter, the information about assisted dying in Oregon and Washington comes

⁴⁴ The annual reports can be downloaded from the health authority websites. See Oregon Health Authority (n.d.) and Washington State Department of Health (n. d.).

from the annual reports unless otherwise stated. California – where assisted dying was introduced in 2016 – has also managed to publish its first report, from which some information has been obtained.

In addition to these reports, academic studies form the main source of information about the practice of assisted dying in these American states. Most research is from Oregon, where assisted dying has been legal the longest. Research on assisted dying in Oregon began before its implementation – perhaps an effect of the implementation being put on hold for three years whilst the legal process was ongoing (see Subsection 3.1.1). Washington has also conducted some research on self-administered assisted dying. The implementation of the Oregon Model in other states has been so recent that no research has yet been published.

The articles in this report that address self-administered assisted dying in Oregon and Washington were found via a search of PubMed, using the simple search string: “assisted death[MeSH Terms] AND (Oregon OR Washington[All Fields])”. The search concluded on 2017, March 15.

After reading abstracts, the articles deemed relevant to the report were obtained. In total, results from approximately 40 articles are presented, which examine the legalisation and application of assisted dying in Oregon and Washington from 1996 onward. As a rule, the articles have been presented regardless of the quality of the study. Instead, comments have been made on any limitations in the studies.⁴⁵

The results of research on self-administered assisted dying in Oregon and Washington concern different patient groups. Some concern patients who *have died* via self-administered assisted dying, or patients who have been *given prescriptions* for self-administered assisted dying. Some studies concern patients who have *requested* self-administered assisted dying, meaning they have submitted a formal oral request for a prescription to their physician (without the request necessarily being granted). Others concern patients who have *demande*d self-administered assisted dying, gen-

⁴⁵ The information presented in this chapter has been chosen to highlight the arguments raised in the Swedish debate. The methodology cannot be treated as a systematic literature review as defined in HTA (health technology assessment).

erally speaking meaning that they have submitted an request or contacted a voluntary organisation that supports patients wishing to access assisted dying. Finally, there are results for patients who have *considered or shown an interest* in self-administered assisted dying, without necessarily having taken the step from thought to deed.

In the Benelux countries, each case of self-administered assisted dying or euthanasia must be submitted to special review committees, who, in addition to assessing whether the law has been followed, compile statistics, albeit in less detail than for Oregon and Washington. Another important source of information about assisted dying in the Netherlands is the national death certificate studies that researchers in the Netherlands have conducted every five years since 1990. The studies are based on a random selection of death certificates from the national death registries and are supplemented with questionnaires to the physicians overseeing the circumstances related to the death. Since 1998, Belgium has conducted similar studies at regular intervals. Apart from these studies, there is a wealth of additional research, particularly from the Netherlands.

There is a relatively large amount of research from Switzerland that examines the implementation of self-administered assisted dying. However, in Switzerland there is no obligation to report cases of self-administered assisted dying to the authorities, which is why there is no systematic monitoring like that in Oregon/Washington and the Benelux countries. Nevertheless, since 2009, cases of self-administered assisted dying have been differentiated from official suicide statistics.

In connection with Canada's euthanasia law entering into force on 2016, June 17, Health Canada was tasked with developing and implemented a national monitoring system. The regulations are expected to enter into force during 2018. Federal and state authorities have agreed that, in anticipation of this, they will compile data on a voluntary basis and present it regularly. In April 2017, a first report was published covering the period until 2016, December 31. In October 2017, a second report was published that covers the

first year of the new legislation.⁴⁶ Some research articles from Canada have also been published.

The purpose of the data from jurisdictions other than Oregon and Washington presented below is to provide a perspective on the findings surrounding the Oregon Model. The primary sources of the research presented are review articles that have surveyed the application of assisted dying, either in general or with a focus on specific aspects.

4.2 Incidence

In Oregon and Washington, self-administered assisted dying makes up 0.3–0.4 per cent of all deaths, and in Switzerland 1.2 per cent. In the Netherlands and Belgium, where euthanasia is permitted, assisted dying is the cause of 4.6 and 1.7–4.6 per cent of all deaths respectively (Belgian figures are uncertain).

In the countries/states where assisted dying is permitted, the number of patients ending their lives by assisted dying is increasing each year.

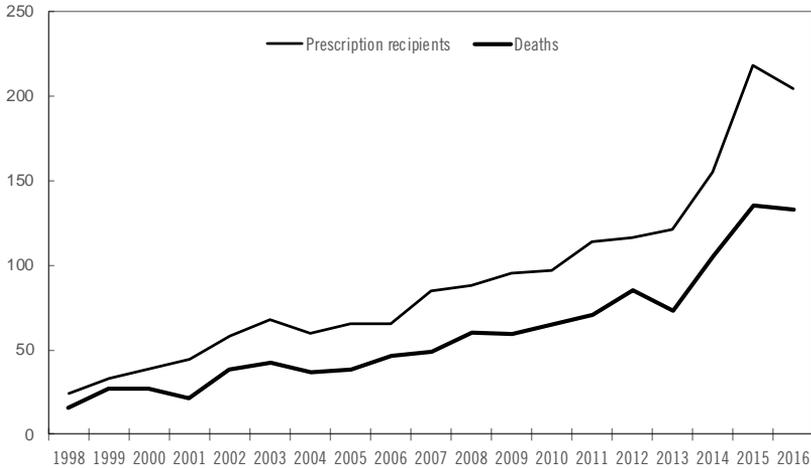
Oregon and Washington

The annual reports from the Oregon health authority show that in 1998 – the first full year when assisted dying was legal in the state – 24 prescriptions were issued for self-administered assisted dying, and 16 cases were completed. These 16 deaths corresponded to 0.5 per thousand deaths in the state. Since then, the number of prescriptions and subsequent deaths has gradually yet steadily increased. In 2016, 204 prescriptions were issued, and 133 patients died from self-administered assisted dying. Of the total number of deaths in Oregon 2016, 3.7 per thousand were as a result of self-administered assisted dying – a slight decrease from 2015. Public statistics from Oregon show that the proportion of patients to utilise their prescriptions since the law entered into force has been

⁴⁶ Health Canada 2017.

approximately two-thirds. The remainder of patients die from other causes.⁴⁷

Figure 4.1 Number of prescriptions recipients/cases of death via self-administered assisted dying in Oregon 1998-2016.



Reasons behind the increase in the issuing of prescriptions for self-administered assisted dying might be both that more people are requesting self-administered assisted dying, and that a larger portion of those have their requests granted. The only data to show the frequency of self-administered assisted dying requests being granted come from a survey conducted in 1999 of 4,000 physicians in Oregon (of whom approximately 2,600 responded). According to this survey, approximately one request in six was granted (i.e. the patient received a prescription), whereas one request in ten concluded with the patient dying as a result of self-administered assisted dying. These figures correspond with official data that suggests that roughly two out of three patients use the medication.⁴⁸

Washington has also seen a successive increase in patients dying from self-administered assisted dying. In the first year of the legis-

⁴⁷ See also Ganzini et al. 2000, and Ganzini et al. 2002.

⁴⁸ Ganzini et al. 2000.

lation, 2009, 65 prescriptions for self-administered assisted dying were issued. Seven years later, 248 prescriptions were issued. 240 of the 248 patients died in 2016, and of the 236 deaths where the death certificates were included in the 2016 report, 192 were as a result of self-administered assisted dying. Self-administered assisted dying accounted for 3.0 per thousand deaths in the state.⁴⁹ No data connected to the frequency of cases permitted has been found for Washington.

From 2016, June 9, when California's law on self-administered assisted dying entered into force, to December 31 the same year, 191 prescriptions for self-administered assisted dying were issued. 111 deaths from self-administered assisted dying were registered in 2016, corresponding to 0.6 per thousand of all deaths.⁵⁰

Other countries

Information reported to the Dutch regional committees that review the application of the euthanasia act shows that an increasing number of Dutch people end their lives through assisted dying. 6,091 cases of assisted dying were reported in 2016, which corresponds to 4.1 per cent of all deaths.⁵¹

If the trend from the national death certificate studies has remained the same, the actual figure may have been even higher. These studies suggest that the degree of reporting is approximately 80 per cent, meaning that every fifth case of euthanasia or self-administered assisted dying is not reported. In the latest study from 2015, 4.6 per cent of all deaths were judged to meet the requirements for euthanasia or self-administered assisted dying – i.e. they occurred as a result of a procedure provided upon the request of a patient with the purpose of hastening death.⁵² However, the number of cases reported to the regional review committees for the

⁴⁹ The figure applies to 2015, as no data for the total number of deaths in Washington for 2016 had been published when this report was submitted for publication. Information for 2015 was obtained from the health authority database: <http://www.doh.wa.gov/Portals/1/Documents/5400/OverviewTable2015.xlsx> (retrieved 2017, July 22).

⁵⁰ California Department of Public Health 2017.

⁵¹ Regional Euthanasia Review Committees 2017.

⁵² van der Heide, van Delden and Onwuteaka-Philipsen 2017

same year comprised only 3.8 per cent of all deaths.⁵³ A previous study of death certificates showed that, in all cases where the physicians did not report the death, the procedure was not classed as assisted dying, but rather as palliative sedation. They also used different medication than that used for “regular” assisted dying. Researchers conducting the death certificate studies believe that this is not a case of under-reporting, but of uncertainties surrounding the effects of medication and the purpose of various procedures.⁵⁴

Reasons for the increase in euthanasia cases are both that more people are requesting assisted dying, and that a larger number of the requests are being granted. Between 2010 and 2015, the proportion of requests for assisted dying increased from 6.7 per cent to 8.4 per cent of all deaths, whilst the rate of approval increased from 45 to 55 per cent.⁵⁵

Euthanasia accounts for the largest proportion of deaths from assisted dying in the Netherlands. According to the death certificate studies, the number of those to die from self-administered assisted dying throughout the years has been between 0.1 and 0.2 per cent.

Death certificate studies from Belgium only include Flanders. According to these studies, the number of deaths in the region from euthanasia are increasing. In 2007, when the first survey after legalisation was conducted, 1.9 per cent of deaths resulted from euthanasia. In 2013, this had risen to 4.6 per cent.⁵⁶ In comparison with the Netherlands, rates of self-administered assisted dying are at a much lower level (approximately 0.5 per thousand) in Belgium, where the legal stance on self-administered assisted dying is unclear (see Subsection 3.2.2). The increase in euthanasia cases is a result of increased demand, but also because the already high rate of approval has become even higher. Death certificate studies showed that, in 2007, the approval rate was 56 per cent, a figure which had increased to 77 per cent by 2013.

⁵³ Information on the total number of deaths in 2015 comes from a compilation from the Royal Dutch Medical Association, KNMG. See: KNMG 2017b.

⁵⁴ Onwuteaka-Philipsen et al. 2012. The picture was confirmed in the most recent study of death certificates, see ZonMw 2017. (The report is in Dutch, but a summary in English is available. Information from the study has also been published in van der Heide, van Delden and Onwuteaka-Philipsen 2017).

⁵⁵ ZonMw 2017.

⁵⁶ Chambaere et al. 2015.

The most recent figures for all of Belgium refer to 2013, where 1.7 per cent of all deaths were as a result of euthanasia.⁵⁷ The difference from the 4.6 per cent stated above can be explained as a result of euthanasia being more common among Flemish people (statistics from the Euthanasia Commission of Belgium show that four out of five euthanasia cases are Dutch-speaking Belgians, who comprise approximately three-fifths of the population⁵⁸), and that the lower figure only includes cases reported to the authorities. Under-reporting of euthanasia to the authorities is more extensive in Belgium than in the Netherlands. In the 2007 death certificate studies, it was discovered that only around half of all cases were reported.⁵⁹

In Luxembourg, a total of 52 cases of euthanasia or self-administered assisted dying were reported between 2009 and 2016.⁶⁰

According to the Swiss Federal Statistical Office, in 2014, 742 people resident in Switzerland died via self-administered assisted dying. The proportion of all deaths to occur through self-administered assisted dying has increased from 0.2 per cent at the start of the 21st century, to 1.2 per cent in 2014.⁶¹ In addition to these people, around 200 foreign citizens each year die in Switzerland via self-administered assisted dying provided by the Dignitas organisation.⁶²

⁵⁷ Dierickx et al. 2016.

⁵⁸ Source: Nationalencyklopedin (ne.se)

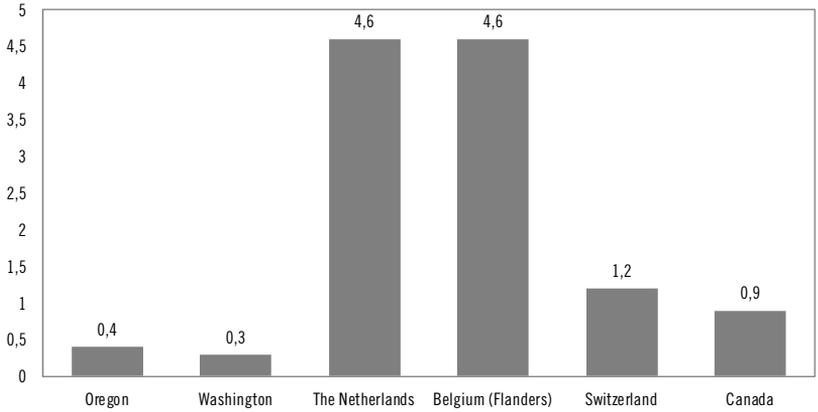
⁵⁹ Smets et al. 2010a.

⁶⁰ Commission nationale de contrôle et d'évaluation de la loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide 2017.

⁶¹ Federal Statistical Office 2016.

⁶² Dignitas (n.d.[b]).

Figure 4.2 Percentage of all deaths via assisted dying in Oregon (2016), Washington (2015), the Netherlands (2015), Flanders (2013), Switzerland (2014) and Canada (2017^a).



^aApplies to the period January 01 to June 30

In Canada, 1,982 cases of euthanasia and self-administered assisted dying have been reported from when the law on assisted dying entered into force on 2016, June 17, until 2017, June 30. Up until 2016, December 31, 0.6 per cent of all deaths were a result of assisted dying. This figure increased to 0.9 per cent in the first half of 2017. Euthanasia is the dominant method in Canada; only five cases of self-administered assisted dying have been reported so far. According to Health Canada, reasons can include prescribers being concerned about the safety of self-administered assisted dying, plus the lack of suitable medication on the Canadian market.⁶³

⁶³ Health Canada 2017.

4.3 The patients

In both Oregon and Washington, three in four patients to receive self-administered assisted dying have been diagnosed with cancer, with one in ten having a progressive neurological disease, most often ALS. Patients with cancer also dominate in other countries. In the Netherlands, Belgium and Switzerland, there are cases of people with severe psychological suffering being granted assisted dying.

In Oregon and Washington, more men than women die from self-administered assisted dying.

The most common age group is 65–74, with the majority being highly educated. The most important reasons for requesting assisted dying in Oregon and Washington are a fear of losing independence, dignity and quality of life towards the end of life, as well as being a burden on one's close relations. Pain and other symptom-related reasons are less important. Financial reasons are rare. In the Benelux countries, hopeless/meaningless suffering (something included in their criteria for assisted dying) are common reasons.

People who request assisted dying are often perceived to be more independent than others. Religious people are less likely to request assisted dying.

4.3.1 Diagnoses

Oregon and Washington

According to the health authority's annual reports, three of four patients to die from self-administered assisted dying in Oregon and Washington have been diagnosed with cancer (the most common forms being lung, breast, bowel, and pancreatic cancer). In relation to the number of patients affected, those with ALS are more likely to choose to end their lives via self-administered assisted dying. As for cancer, patients with ovarian, pancreatic or oral cancer are those most likely to request self-administered assisted dying. It is over twice as common for patients with these cancers to choose self-

administered assisted dying in comparison to patients with lung cancer (data apply to Oregon).⁶⁴

Table 4.1 Distribution in per cent between the different diagnosis groups of patients who have died as a result of self-administered assisted dying (Oregon and California⁶⁵), or who have received a prescription for assisted dying (Washington).

Diagnosis group	Oregon		Washington	California
	2016	1998-2016	2016	2016
Cancer	79	77	77	59
ALS	7	8		
Neurodegenerative diseases (incl. ALS)			8	18
COPD	2	4		
Respiratory diseases (incl. COPD)			8	6
Cardiac diseases	7	3	8	6
AIDS	0	1		
Other illnesses	6	7	2	9

Public statistics from Washington do not include diagnoses of other diseases, but in Oregon other diseases include benign or unclear tumours, respiratory diseases other than COPD, other neurodegenerative diseases than motor neurone disease, musculoskeletal systems disorders, viral hepatitis, diabetes, cerebrovascular disease and cirrhosis of the liver. Illnesses such as depression or dementia have not been reported as primary diagnoses in Oregon and Washington. This is in line with the requirement for a terminal illness and having decision-making capacity.

Other countries

Cancer, neurodegenerative diseases and cardiovascular diseases belong to the most common diagnoses for patients to die from assisted dying in the Benelux countries, Switzerland and Canada. These countries have no requirements for terminal illness, and so

⁶⁴ Hedberg, Hopkins and Kohn 2003; Hedberg et al. 2009.

⁶⁵ Source: California Department of Public Health 2017.

there are cases of assisted dying being granted on the basis of mental illness or multimorbidity.

Table 4.2 Distribution in per cent between different diagnosis groups of patients to die from euthanasia or self-administered assisted dying in Belgium (2015), Luxembourg (2009-2016), the Netherlands (2016), Switzerland (2010-2014), and Canada (2017^a).⁶⁶

Diagnosis group	Belgium	Luxembourg	The Netherlands	Switzerland	Canada
Cancer	68	83	68	42	63
Neurodegenerative diseases	7	13	7	13	13
Cardiovascular diseases	5		5	11	17 ^g
Pulmonary and respiratory diseases	3		4		
Multimorbidity			4		
Musculoskeletal systems disorders				10	
Dementia			2	1	
Mental illness	3 ^b		1	3 ^e	
Other diagnoses	14 ^c	4	9 ^d	20 ^f	7

^a Applies to the period January 01 to June 30

^b Including dementia

^c Including cases with more than one diagnosis

^d Including cases with more than one diagnosis

^e Depression alone

^f Also includes cases of blindness, chronic pain and multimorbidity

^g Including pulmonary and respiratory diseases

In recent years, the regional euthanasia review committees have seen an increase in the willingness of Dutch physicians to administer assisted dying for cases of psychological suffering.⁶⁷ The frequency has increased from 0.4 to 1.0 per cent of all cases between

⁶⁶ Commission fédérale de contrôle et d'évaluation de l'euthanasie 2016 (Belgium); Commission nationale de contrôle et d'évaluation de la loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide 2017 (Luxembourg); Regional Euthanasia Review Committees 2017 (the Netherlands); Federal Statistical Office 2016 (Switzerland); Health Canada 2017 (Canada).

⁶⁷ Regional Euthanasia Review Committees 2013.

2011 and 2016. The number of people to suffer from multimorbidity decreased between 2013 and 2016, from 5.7 to 4.0 per cent.⁶⁸

In a study where 66 specific cases of euthanasia among people with psychiatric disorders in the Netherlands were investigated, the most common diagnoses were depression (55 per cent), post-traumatic stress disorder and other symptoms of anxiety (42 per cent). 26 per cent, including a proportion of patients with depression, experienced psychosis or psychotic symptoms. There were also cases of people with cognitive impairments (6 per cent) and eating disorders (6 per cent) receiving assisted dying. The predominant number of patients had several psychiatric disorders, and half had personality disorders or other personality-related problems. Half of the patients had a history of attempted suicide.⁶⁹

The number of patients not suffering from terminal diseases to receive euthanasia in Belgium has increased over time. In 2003, they comprised 8 per cent of all reported cases, and by 2013, 15 per cent. Neuropsychiatric disorders and multimorbidity belong to the diagnoses increasing in frequency.⁷⁰

In a study of 100 Belgian patients with psychiatric disorders who requested assisted dying, depression dominated (58 per cent). Just as in the Dutch study, there was a marked number of people with personality disorders (50 per cent). 19 per cent had Asperger's Syndrome. Here there were also many cases where patients had several mental health disorders. Almost half (48 per cent) were granted euthanasia (the authors did not report the approval frequency by different diagnostic groups). Of the 52 per cent denied euthanasia, four died by suicide, as did two of the 48 who had been granted euthanasia.⁷¹

Among the patients in Switzerland to receive help in dying through the EXIT organisation, the number of cases where the patient suffered from a non-fatal illness increased between 1990 - 2000 (22 per cent), and 2001–2004 (34 per cent).⁷² Information on the subsequent development has not been found.

⁶⁸ Data from the review committees' annual report 2013, and the Royal Dutch Medical Association. See: Regional Euthanasia Review Committees 2013; KNMG 2017b.

⁶⁹ Kim, De Vries and Peteet 2016.

⁷⁰ Dierickx et al. 2016.

⁷¹ Thienpont et al. 2015.

⁷² Fisher et al. 2008.

4.3.2 Demographics and socioeconomics

Oregon and Washington

When viewed over the entire period of the Death with Dignity Act in Oregon, slightly more men than women have died by self-administered assisted dying (52 per cent men, 48 per cent women). In 2016, this was 54 per cent men and 46 per cent women. The gender distribution in Washington for 2016 was even. Yet in previous years there was a tendency for more men than women to receive prescriptions for self-administered assisted dying.

Table 4.3 Age range of patients 2016 (per cent).

Age	Oregon	Washington
18-44	2	3
45-54	4	5
55-64	14	22
65-74	39	25
75-84	23	28
85+	18	18

In Oregon, self-administered assisted dying is most common in the 65–74 age group, a pattern consistent since the legalisation of self-administered assisted dying. The tendency in Washington has been the same. However, 2016 was the first time the majority of patients to receive self-administered assisted dying were in the 75–84 age group.

If, instead, one compares with the total number of deaths in each age group, we see that self-administered assisted dying is commoner the younger one is. In a follow-up conducted ten years after the introduction of the Death with Dignity Act, 6.5 per thousand of all deaths from 1998 to 2007 in the 18–34 age group were the result of self-administered assisted dying, but only 1.5 per thousand in the 85+ age group.⁷³ One suggestion why the very elderly are underrepresented is that the older a person becomes, the

⁷³ Hedberg et al. 2009. According to a study in Oregon, more elderly people choose to hasten death by refusing food and drink. In these instances, the reasons for wanting to hasten death are generally the same as for self-administered assisted dying. See Ganzini et al. 2003a.

harder it is to meet the criterion of being capable due to cognitive impairments. Another explanation may be that the elderly tend to have a more negative opinion on assisted dying.⁷⁴ Statistics from the healthcare authority have shown that in recent years there has been an increase in the number of patients over 85 to receive self-administered assisted dying. During the 1998-2013 period, the oldest group formed 12 per cent of all patients to die via self-administered assisted dying in Oregon. Between 2014 and 2016, this portion was between 18 and 24 per cent.

Data from the healthcare authorities shows that in both Oregon and Washington, more than nine out of ten people to die from self-administered assisted dying are white. Just under fifty per cent are married, one quarter are widows/widowers, one quarter divorced and the remainder unmarried. Around half hold a bachelor's degree, whilst approximately five per cent have less than high school education.

Several studies have underlined how education is the single most important demographic or socioeconomic factor differentiating the patients in Oregon who request or die from self-administered assisted dying from other patients.⁷⁵ Some studies suggest that, among the patients suffering from the same underlying illnesses, patients who hold a bachelor's degree are seven to nine times more likely to die from self-administered assisted dying and patients who studied at college level two to three times more likely to die from self-administered assisted dying compared to patients who only completed compulsory schooling.

Whereas more patients with university degrees die from self-administered assisted dying, there is a different picture if you look at the patients who *consider* self-administered assisted dying. In a study from 2000–2002 where questions were asked of relatives of around 2,000 randomly selected deceased Oregon residents (approximately 1,400 responded), it was just as common for people with high school education to have considered self-administered assisted dying.⁷⁶ The authors believe that this could suggest that educational and/or interpersonal resources are required in order to

⁷⁴ Hedberg and Tolle 2009.

⁷⁵ Hedberg, Hopkins and Kohn 2003; Battin et al. 2007. Also see Smith et al. 2015.

⁷⁶ Tolle et al. 2004. The sample did not include people who suddenly died from conditions such as cardiac arrest.

process the bureaucratic elements of self-administered assisted dying.

A significant difference concerning marital status has been found in Oregon. Self-administered assisted dying is almost twice as common among divorced and unmarried people than among people who are married.⁷⁷ Those who die through self-administered assisted dying are also younger when compared to the patient group as a whole. One study showed that the median age was 69 in the former group, and 76 in the latter.⁷⁸

There are no signs that minorities are overrepresented among those who die from self-administered assisted dying in Oregon. Of the 1,127 people to die from self-administered assisted dying up to 2016, 96.5 per cent were white, 1.3 per cent Asian, and 1.1 per cent Hispanic. Only one African-American chose to end their life through self-administered assisted dying. For comparison, Asians, Hispanics and African-Americans comprise 4, 13 and 2 per cent of Oregon's population respectively.⁷⁹ According to the study among relatives of 1,400 deceased patients in Oregon, no African-American patients had considered self-administered assisted dying, whereas 20 per cent of white people had.⁸⁰

One study examining the situation of vulnerable groups in Oregon and the Netherlands found that only one per cent of patients who died from self-administered assisted dying in Oregon between 1998 and 2006 had no healthcare insurance, whilst 17 per cent of the adult population had no insurance. The authors concluded that there was no increased likelihood of self-administered assisted dying among people living in poverty.⁸¹ The proportion of those uninsured among the patients who died from self-administered assisted dying has not changed since the study was conducted. In 2016, one per cent of the patients in Oregon had no insurance, even fewer in Washington.

Between 2009 and 2011, 24 patients died from self-administered assisted dying at the Seattle Cancer Center Alliance outpatient clinic. In this limited group, there was no over-representation of

⁷⁷ Hedberg, Hopkins and Kohn 2003; Hedberg et al. 2009; Smith et al. 2015.

⁷⁸ Hedberg, Hopkins and Kohn 2003.

⁷⁹ Source: United States Census Bureau.

⁸⁰ Tolle et al. 2004.

⁸¹ Battin et al. 2007.

minorities or people on low incomes.⁸² Throughout the state of Washington, 97 per cent of those to die from self-administered assisted dying in 2016 were “non-Hispanic whites” – a group comprising 70 per cent of the population.⁸³

Of the 111 people to die from self-administered assisted dying in 2016 in California, 54 per cent were women. The median age was 73 years. 58 per cent of patients held at least a bachelor’s degree. Those without insurance comprised four per cent. 90 per cent were white, 5 per cent Asian, 2.5 per cent Hispanic, and 2.5 per cent black.⁸⁴

Other countries

In both Belgium and the Netherlands, more men than women die from assisted dying. However, women dominate the group of patients in Belgium and the Netherlands who receive assisted dying for psychological suffering; studies suggest they make up 70 per cent or more of patients.⁸⁵

In Switzerland, women predominate among the patients who die from self-administered assisted dying.⁸⁶ Nevertheless, one study established that this majority could be explained by the age factor – i.e. self-administered assisted dying was more common among the highest age groups, in which women dominate.⁸⁷ According to statistics from the Swiss Federal Statistical Office, between 2010 and 2014, three out of five of those to die from self-administered assisted dying were 75 or older.

⁸² Loggers et al. 2013.

⁸³ Sources: Health authority annual report and the United States Census Bureau.

⁸⁴ California Department of Public Health 2017.

⁸⁵ Kim, De Vries and Peteet 2016; Thienpont et al. 2015.

⁸⁶ Federal Statistical Office 2016

⁸⁷ Steck et al. 2014.

Table 4.4 The gender distribution in per cent among patients to die from assisted dying in Belgium (2015), the Netherlands (2016), Switzerland (2014) and Canada (2017^a).⁸⁸

	Belgium	The Netherlands	Switzerland	Canada
Women	48	49	57	47
Men	52	51	43	53

^a Applies to the period January 01 to June 30

Table 4.5 Age distribution in per cent among patients to die from assisted dying in Belgium (2015), the Netherlands (2016), and Switzerland (2010-2014).⁸⁹

	Belgium	The Netherlands	Switzerland
0-59 years old	16	14	18
60-79 years old	48	53	52
80 or above	36	33	30

^a The figures for Switzerland apply to age groups 0-64, 65-84 years and 85 years or above

In relation to the total number of deaths in the respective age groups, assisted dying in the Netherlands is most common among those under 65 and least common with people over 79.⁹⁰ In Belgium, the average age of patients to die from euthanasia is lower than of all the people who die.⁹¹ In a Belgian study addressing assisted dying among people with psychiatric disorders, the median age of these patients was significantly lower (47) than for other patients dying from assisted dying.⁹²

In the Netherlands, assisted dying can be granted from the age of twelve years. In the 2002–2016, a total of eight underage patients received assisted dying.⁹³ No reports of euthanasia of underage patients have been submitted to the Belgian authorities up until 2015 (euthanasia was legalised for children in Belgium in 2014),

⁸⁸ Commission fédérale de contrôle et d'évaluation de l'euthanasie 2016 (Belgium); Regional Euthanasia Review 2017 (the Netherlands); Health Canada 2017 (Canada); Federal statistical office 2016 (Switzerland).

⁸⁹ Commission fédérale de contrôle et d'évaluation de l'euthanasie 2016 (Belgium); Regional Euthanasia Review Committees 2017 (the Netherlands); Federal Statistical Office 2016 (Switzerland, estimated from diagram).

⁹⁰ Onwuteaka-Philipsen et al. 2012.

⁹¹ Smets et al. 2010b.

⁹² Thienpont et al. 2015.

⁹³ Information from the review committees' reports. See: Regional Euthanasia Review Committees 2016 and 2017.

however information from the media suggests that a 17-year-old Belgian died from euthanasia in 2016.⁹⁴

As in Oregon and Washington, assisted dying is more common in Belgium among the more highly educated.⁹⁵ (Nevertheless, a study found that, if the frequency of cancer cases were controlled for, most of the difference disappeared.⁹⁶) A data analysis from the 2001 study of death certificates in the Netherlands showed that assisted dying was more common in affluent areas.⁹⁷ In Switzerland, assisted dying was significantly more common among the highly educated and people in affluent areas, as well as among those living alone or the non-religious.⁹⁸

In a systematic review from 2011, the authors examined research that investigated various end-of-life decisions, including euthanasia and self-administered assisted dying, and found a variation in its occurrence between social groups. When the results of the various studies (conducted in different countries) were compiled in a meta-analysis, findings showed that assisted dying – as well as palliative sedation and procedures to shorten life without consent – were significantly more common among younger patients, whereas the decision to abstain from life support was more common among the elderly. No significant differences regarding assisted dying were found between the genders, whilst palliative sedation and procedures to shorten life without consent were more common among men, and the decision to abstain from life support was more common among women. The patients included in the meta-analysis to die from assisted dying were somewhat more highly educated, but the differences were not significant. On the other hand, it was found that patients with less education received intensified symptom alleviation to a significantly lower extent. Instead they received palliative sedation to a significantly higher extent.⁹⁹

⁹⁴ BBC 2016.

⁹⁵ Dierickx et al. 2015

⁹⁶ Chambaere et al. 2013.

⁹⁷ Battin et al. 2007.

⁹⁸ Steck et al. 2014.

⁹⁹ Rietjens et al. 2012.

4.3.3 Grounds for requesting assisted dying

Oregon and Washington

After a patient has received a prescription for self-administered assisted dying, the attending physician must complete a questionnaire from the health authorities, in which the patient's reasons for requesting self-administered assisted dying must be stated (the alternatives are pre-formulated). This data is presented in the annual statistics reports. As evident in the table below, the reports show that the majority of patients had more than one reason for their decision.

Table 4.6 Patients' reasons for requesting self-administered assisted dying according to their physician (data for 2016). Percentage of all patients (respondents could provide more than one reason).¹⁰⁰

Grounds for requesting assisted dying	Oregon	Washington
Less able to engage in activities making life enjoyable	90	84
Losing autonomy	90	87
Loss of dignity	65	66
Losing control of bodily functions	37	43
Burden on family, friends/caregiver	49	51
Inadequate pain control or concern about it	35	41
Financial implications of treatment	5	8

Several studies from Oregon that have asked patients¹⁰¹, relatives¹⁰² or physicians¹⁰³ and other healthcare staff¹⁰⁴ confirm that loss of independence, reduced quality of life, loss of dignity and the wish to control the circumstances of death were more important reasons for choosing self-administered assisted dying than the physical pain experienced. On the other hand, avoiding *future* pain seems to be an important reason for the patients. On a scale of one to five, where five indicated that the reason was very important, the median for this reason was five when ranked by the patients themselves, and four when ranked by their relatives. For reasons of avoiding

¹⁰⁰ Source: Health Authority annual reports.

¹⁰¹ Ganzini, Goy and Dobscha 2009.

¹⁰² Ganzini, Goy and Dobscha 2009; Sullivan, Hedberg and Fleming 2000.

¹⁰³ Chin et al. 1999; Ganzini et al. 2000.

¹⁰⁴ Ganzini et al. 2002.

existing pain, the median stated by patients on the scale was one, with the relatives stating two. There was the same tendency for other physical symptoms.

Healthcare staff in Oregon believe that one prominent reason for requesting assisted dying is the feeling of being ready to die, and that continued existence is pointless. This idea is not shared by patients and their relatives. However, several studies have confirmed that one relatively important reason is that patients do not want to be a burden to others. Yet the patients are not concerned about being a financial burden. When asked to rank this on a scale from one to five, the median was one for both patients and relatives. Other studies suggest that financial concerns or lack of social support are less important factors. This could possibly be linked to the majority of patients requesting self-administered assisted dying belonging to a higher socioeconomic group.

Results from research in Washington are limited, although an in-depth interview study with patients who requested self-administered assisted dying and/or their relatives shows that reasons are evenly distributed between illness-related factors (feeling tired or uncomfortable, pain, loss of function), more existential concerns (loss of sense of self, desire for control) and fears about the future.¹⁰⁵ The physical pain experienced was the least important factor. Another report from the same study showed that, for those patients waiting to use the medication until they had less than one month to live,¹⁰⁶ illness-related factors were more decisive for the timing of death than for those using the medication when they had one to six months left to live. In this group, the fear of losing control over their fate was more significant.¹⁰⁷

Even if the symptom-related factors were believed to be less important reasons for those *dying* from self-administered assisted dying, the study of relatives of 1,400 deceased Oregon residents from 2000–2002 showed a clearer link between the pain experi-

¹⁰⁵ Pearlman et al. 2005. This study was conducted before self-administered assisted dying was permitted in Washington. Back et al. 1996 (also conducted before self-administered assisted dying was legalised in Washington) report a similar situation. The fear of losing control, becoming a burden and losing independence were the most common reasons for requesting self-administered assisted dying or euthanasia, with pain experienced and financial concerns being the least common.

¹⁰⁶ After retrospective evaluation.

¹⁰⁷ Starks et al. 2005.

enced and other symptoms in the final week of life, and the probability for having *considered* self-administered assisted dying.¹⁰⁸ One plausible explanation raised in a comment on the study is that, once the symptoms are so severe that they lead the patient to consider self-administered assisted dying, the illness has progressed so far that the patient is unable to follow all the steps necessary for an application, or they do not meet the requirement of being capable.¹⁰⁹

The authors of one of the studies observed that many patients who request self-administered assisted dying appear to be anticipating a forthcoming situation that they fear will be unbearable (with more weight on existential rather than purely physical suffering), rather than reacting to existing suffering.¹¹⁰ This may suggest that the wish for security is an important factor behind several patients' wish for self-administered assisted dying. Prior to the legalisation in Oregon, when motor neurone disease patients in Oregon and Washington were asked about their interest in assisted dying, four out of five who responded that they would consider requesting self-administered assisted dying if it were legal suggested that they would save the prescription for future use, which the authors believe could demonstrate the importance of the security factor.¹¹¹ An additional observation to support the assumption that security is an important motivation can be found in a study conducted by a cancer clinic in Seattle, Washington. Patients admitted to the clinic who had received a prescription for self-administered assisted dying and their relatives often expressed gratitude after the prescription was issued – regardless of whether they collected it and used the medication or not. A feeling of control in an uncertain situation was often mentioned.¹¹²

¹⁰⁸ Tolle et al. 2004.

¹⁰⁹ Ganzini and Dobscha. 2004.

¹¹⁰ Ganzini, Goy and Dobscha 2009.

¹¹¹ Ganzini et al. 1998.

¹¹² Loggers et al. 2013.

Other countries

In the Dutch death certificate studies, physicians are asked about the most important grounds for granting assisted dying. In the most recent survey from 2015, the most common responses were no hope of improvement (82 per cent), the patient's request (80 per cent), severe symptoms apart from pain (60 per cent), loss of dignity (59 per cent), expected suffering (44 per cent) and pain (40 per cent).¹¹³ In a study in which relatives of patients in the Netherlands who had died by euthanasia or self-administered assisted dying were asked about the patient's reasons for requesting assisted dying, the most common responses were hopeless suffering, loss of dignity, no prospect of recovery, meaningless suffering, dependency on others in managing everyday life, general weakness, and pain (Table 4.7)¹¹⁴

The most recent death certificate study from Flanders (2013) suggest that the most common reason for physicians granting euthanasia were the patients' requests (88 per cent), physical and/or mental suffering (87 per cent), no prospect of improvement (78 per cent), loss of dignity (52 per cent), expected further suffering (48 per cent), low quality of life (45 per cent), life not to be prolonged needlessly (31 per cent), being tired with life (25 per cent), family's request (23 per cent) and an unbearable situation for family (14 per cent).¹¹⁵ In another study in which physicians were asked why their patients had requested euthanasia, the most important reasons stated were suffering without prospect of relief, loss of dignity, pain, general weakness, and not wanting to be a burden on others (Table 4.7).¹¹⁶

A Swiss study from 2001–2004 suggested that the most important reasons for patients dying from self-administered assisted dying were pain, the need for long-term care, the desire to control the circumstances of one's death, loss of dignity and neurological symptoms (Table 4.7). Generally speaking, the consistency between the patients' motives for requesting self-administered dying and their physicians' reasons for granting self-administered assisted

¹¹³ ZonMw 2017.

¹¹⁴ Georges et al. 2007.

¹¹⁵ Dierickx et al. 2015.

¹¹⁶ Van Wesemael et al. 2011.

dying was high. Psychological or existential motives (such as controlling the conditions of one's death, loss of dignity, and low quality of life) were, however, more prominent among patients than among their physicians.¹¹⁷ The authors propose that one explanation could be that physicians find medical grounds more legitimate, and that regulations in Switzerland focus on medical evaluations (see Subsection 3.3.1).

Table 4.7 Reasons behind patients' requests for assisted dying, according to their physicians (Belgium), relatives (the Netherlands) and the patients themselves (Switzerland). Percentage of all patients (respondents could provide more than one reason).

Grounds for requesting assisted dying	Belgium	The Netherlands	Switzerland
Suffering without hope of relief	72	74	
No prospect of recovery		43	
Meaningless suffering		36	
Pain	34	32	58
General weakness	32	33	26
Dyspnoea/fear of suffocation	7/13	20 ^a	23 ^b
Vomiting	3	12	
Neurological symptoms			32
Insomnia and loss of concentration			13
Visual and aural impairments			11
Depression	12	5	
Invalidity/immobility	14	18	30
Need of long-term care			39
Loss of dignity	44	56	38
Dependence	22	35	
Burden on others	32	22	
Weariness of treatment			21
Tired of life	26	8	12
Wish to control the circumstances of death			39
Less able to participate in activities making life enjoyable			18

^a Fear of suffocation
^b Dyspnoea

¹¹⁷ Fisher et al. 2009.

Currently there is little data from Canada on patients' reasons for requesting assisted dying. According to a report from the University Health Network in Toronto, where a programme to provide euthanasia as part of hospital care has been implemented, loss of autonomy was the predominant reason for the 19 patients to have died from euthanasia at one of the hospitals included in the network leading up to 2017, March 08. Avoiding the loss of dignity, not being a burden on others, and not being able to enjoy one's life were other common reasons, whereas insufficient symptom control was only stated in a few cases.¹¹⁸

4.3.4 Personality characteristics and outlook on life

Oregon and Washington

As we have noted, patients in Oregon and Washington who request assisted dying differ in several demographic factors from other patients with the same illnesses. Level of education is the most prominent, and to a lesser extent, age and marital status.

A great deal of research shows that there are also factors linked to personality and outlook on life that define the patient group that requests self-administered assisted dying. In a small case-control study with the first 15 patients in Oregon to die from self-administered assisted dying after its legalisation in 1997, the physicians responsible observed that the patients who received self-administered assisted dying were significantly more concerned about their loss of autonomy and losing control over their bodily functions.¹¹⁹ Many of the physicians who granted self-administered assisted dying reported that their patients were people who had been decisive and independent throughout their life, or had a long-standing belief that control over death was important. This is what led them to request self-administered assisted dying – not pain or financial concerns. According to the physicians, only one of the 15 patients had insufficient pain control, whereas 15 of the 43 in the control group did (however, because of low participant numbers the difference was not significant)

¹¹⁸ Li et al. 2017.

¹¹⁹ Chin et al. 1999.

Patients who choose self-administered assisted dying being more concerned about losing control and independence than other patients is something which is supported by a study of nurses working with palliative care in Oregon. Yet, in terms of pain, anxiety, dyspnoea and fear of dying, the nurses believed that the patients who received self-administered assisted dying had milder symptoms than other patients.¹²⁰

Another study asked relatives of 84 patients who had persistently requested self-administered assisted dying (regardless of whether or not this was granted) to describe the deceased person's attachment style.¹²¹ The control group comprised relatives of 63 patients who met the criteria for self-administered assisted dying, but who died without having requested the procedure. In a test that differentiated between four attachment styles (secure, preoccupied, fearful and dismissive)¹²², relatives of patients who had requested self-administered assisted dying more often described the patient as dismissive (without a great need for close emotional relationships, and particular about their independence) than those in the control group (however, the difference was only marginally significant). At the same time, the patients who requested self-administered assisted dying were described as being significantly less fearful in their attachment style.

When the study was conducted, the tool for determining attachment patterns had not been validated for indirect use via relatives. Furthermore, the recruitment method did not guarantee that the result was representative for all patients, either in the case or control group. Hence, the study should be interpreted with a degree of caution. However, similar results did arise in a case-control study from 2015, where 55 patients in Oregon who demanded administered assisted dying were compared to 39 patients who did not.¹²³ This study also showed that the patients who demanded self-administered assisted dying displayed a higher level of dismissive attachment than those who did not. This result should also be taken with a degree of caution due to the low number of partici-

¹²⁰ Ganzini et al. 2002.

¹²¹ Oldham et al. 2011.

¹²² Bartholomew and Horowitz 1991.

¹²³ Smith et al. 2015.

pants. Nevertheless, the differences observed were statistically significant.

The same study showed a stronger inverse correlation between the interest in self-administered assisted dying and spirituality – a complex concept that comprises aspects such as the feeling of hope and meaning, connectedness, reconciliation and religious belief.¹²⁴ Other studies from Oregon have also shown that patients who consider self-administered assisted dying are less religious than others.¹²⁵

Qualitative studies have also been conducted in Oregon regarding patients who request self-administered assisted dying. In an in-depth interview study with 35 physicians in Oregon who had patients who requested self-administered assisted dying, it became clear that the physicians viewed these patients as strongly independent people, used to control and independence throughout their lives. The physicians believed that, for many patients, self-determination was almost a philosophy of life. The patients were most concerned about the idea of losing control and becoming dependent on care, and this was also the most important reason behind requesting self-administered assisted dying. Being a burden on others them was also an off-putting thought. According to the physicians, this also applied in cases where the family members of the patient said that taking care of them was meaningful and pleasant.¹²⁶

Another recurring description was that the patients were strong-willed, almost stubborn people. This is also reflected in their request for assisted dying. The physicians believed they had decided they wanted to die via self-administered assisted dying, and, in many cases, they were not interested in the alternatives offered – including palliative care. A number of patients were willing to consider palliative care once they had been given their prescription. As a rule, they stood by their decision, even in cases where those close to them opposed it.

This study has certain limitations. It is small, and the results cannot be further generalised to all patients who request self-

¹²⁴ Kellehear 2000.

¹²⁵ Tolle et al. 2004; Smith et al. 2011.

¹²⁶ Ganzini et al. 2003b.

administered assisted dying. Furthermore, there is a risk that the physician's personal attitude to self-administered assisted dying could have influenced how obstinate they felt the patient was. Nevertheless, the results point in the same direction as other data. If these different sources are combined, there is an image of self-administered assisted dying – in Oregon at least – as a strategy for independent patients to meet future threats linked to death, where dependency and the loss of control are believed to be worse than the physical symptoms. It is a case of the patients being able to die as they lived, as “king of the castle” and consequently retain their dignity. These patients may view offers of further care as a threat rather than a promise, at least if it is care beyond their control.

Other countries

In an in-depth interview study with relatives of eight patients who died from self-administered assisted dying conducted in the Italian speaking part of Switzerland, the majority described the deceased as independent people unwilling to become dependent on others and lose control. The fear of losing dignity and becoming dependent on others for coping with everyday life and bodily functions were strong motivations behind choosing self-administered assisted dying. Often, their physical symptoms were under control at the time they made their decision. Many of the patients were sceptical about palliative care.¹²⁷

4.4 The practical application

In Oregon and Washington, the absolute majority of patients die in their home environment. Three to five per cent of cases report complications. In six cases in Oregon and two in Washington, the patient has woken up again after consuming the medication.

The majority of patients in Oregon and Washington die shortly after their medication is prescribed. A small percentage

¹²⁷ Gamondi, Pott and Payne 2013.

live beyond six months or more (figures vary from 3 to 10 per cent).

In Oregon and Washington, there is no systematic follow-up to show if there are cases of assisted dying that do not follow the regulations. In the Netherlands and Belgium, such research shows that there are patients who have not explicitly requested assisted dying who receive the procedure, but the extent of this is decreasing.

4.4.1 Where and how does a person die?

Oregon and Washington

Annual reports suggest that the majority of patients in Oregon and Washington die from self-administered assisted dying in their home environment (89 and 88 per cent respectively for 2016). One reason for this is that Oregon has a clear policy that as few patients as possible die in hospitals; another is that many hospitals do not allow self-administered assisted dying on their premises. Additionally, palliative care in the USA is predominantly provided in the home, and the majority of patients are receiving palliative care when they die.¹²⁸

In neither Oregon nor Washington are there any requirements for a patient's physician or any other medical professional to be present when the medication is consumed. According to the Washington health authorities, in 2016, in 9 per cent of cases the patient's physician was present when they took the medication, and other medical professionals in 51 per cent of cases (there is no data for 28 per cent of cases). In cases where another medical professional is present, they are often volunteers from the Compassion and Choices non-profit organisation that supports patients' end of life choices.¹²⁹ In Oregon in 2016, the patient's physician was present in 10 per cent of cases. Statistics on other healthcare staff are

¹²⁸ After a telephone conversation with Linda Ganzini 2017, March 16. There are examples of where routines have been developed to manage requests for assisted dying within the scope of hospital duties. One example is the previously mentioned cancer clinic in Seattle, where a programme has been developed where the clinic's physicians contribute to evaluating requests for assisted dying and prescribing medication. See Loggers et al. 2013.

¹²⁹ Campbell and Black 2014.

less clear in the public statistics from Oregon, however it is also common for a volunteer from Compassion and Choices to be present in Oregon.¹³⁰

According to the Oregon healthcare authorities, the 204 prescriptions were issued in 2016 by 102 different physicians, of whom each physician issued between one and 25 prescriptions. In Washington, the 248 prescriptions in 2016 were issued by 140 different physicians. In Oregon, patients and physicians had known each other from one week to 29 years at the time of the patient's death (the median was 18 weeks). In Washington, 53 per cent of the patients had known their physician for less than 25 weeks, whereas 36 per cent had known their physician for at least one year (the time varied from less than one week to 31 years). In 2016, the median waiting time in Oregon from the first request for assisted dying and death was 56 days. Washington has reported that 89 per cent of the patients died within 25 weeks of the first request.

Healthcare insurance or the state healthcare programme does not cover the cost of the medication; instead, the patient must pay for it themselves. The primary medications used in Oregon and Washington were previously barbiturates (pentobarbital or secobarbital). In recent years, the price of secobarbital has increased considerably, to between 3,000 and 5,000 dollars per dose. Consequently, in 2015 physicians in Washington began prescribing a combination of phenobarbital, chloral hydrate and morphine that costs around 500 dollars per dose. Some patients experienced a powerful burning sensation from this combination, so, as of 2016, Washington uses a combination of diazepam, digoxin, morphine and propranolol at a price of between 300 and 600 dollars per dose.

¹³¹

Among patients in Washington dying from self-administered assisted dying in 2016, 57 per cent lost consciousness within ten minutes of taking the medication (no data is available for 20 per cent). 53 per cent died within 90 minutes (no data is available for 17 per cent). The longest period was eleven hours until loss of consciousness and 22 hours until death. In Oregon, from 1998 to 2016, the median time between ingestion and unconsciousness has been

¹³⁰ Campbell and Cox 2010.

¹³¹ Aleccia 2016.

five minutes and between ingestion and death 25 minutes (data is available for approximately half of the patients).

Of the total 829 cases in Washington between 2009 and 2016 where the patient had taken medication for self-administered assisted dying, 765 cases (92 per cent) have data on complications. A total of 23 cases of complications were reported (3 per cent). Regurgitation was reported in 16 cases, seizures in one case, and other complications in four cases. In two cases (0.3 per cent) both from 2009, the patient was reported to have woken up again after having taken the medication. For all cases in Oregon since 1997 where data is available, (584 out of 1,127 cases), regurgitation/problems ingesting were reported in 30 cases, an equivalent of 5 per cent of cases. In Oregon, there are six reported cases from 2012 or earlier where the patient regained consciousness after taking the medication. In the majority of cases, the patients died from their underlying illness (with one patient living for three months). These cases are not included in Oregon's statistics on self-administered assisted dying, but in relation to the total number of deaths via self-administered assisted dying, the six cases are the equivalent of 0.5 per cent.

Other countries

In the Netherlands, the patients receiving euthanasia die at home (81 per cent), and the person administering the injection is their regular GP (85 per cent). A relatively new phenomenon is the "end of life clinic", to which patients can turn if their own physician has refused their request for assisted dying. The organisation is run by a team of physicians and nurses who visit the patients at home.¹³² In 2016, physicians from these clinics were responsible for 8 per cent of the cases of assisted dying reported to the regional euthanasia review committees.¹³³

In Belgium, death in hospital is more common than for other countries (42 per cent). Other patients die at home (44 per cent), in nursing homes (12 per cent) or in another place (2 per cent).¹³⁴

¹³² Levensindekliniek (n.d.).

¹³³ Regional Euthanasia Review Committees 2017.

¹³⁴ Commission fédérale de contrôle et d'évaluation de l'euthanasie 2016.

In Canada, approximately two patients out of the five in the first half of 2017 died in the hospital, and just as many at home. Other patients died in nursing homes or other locations. However, there is a large variation between the different states, which may be as a result of different regulations and access to care infrastructure.¹³⁵

As regards complications, a study from 2000 found that, where 649 cases of euthanasia and self-administered assisted dying were examined in the Netherlands, 10 per cent of self-administered assisted dying cases experienced “technical” problems (for example difficulties in swallowing). Complications (for example seizures and vomiting) occurred in 9 per cent of cases. In 2 per cent of cases, the patient woke up, and in 12 per cent of the cases, death occurred after a longer period than anticipated, or not at all. The complications frequency was lower for euthanasia than for self-administered assisted dying. There were technical problems in 4 per cent of euthanasia cases (for example, difficulties in finding a vein), and an equal proportion of cases encountered problems such as seizures or vomiting. In a further 1 per cent of cases, the patient woke up, and in 4 per cent of the cases, death occurred after a longer period than anticipated or not at all. The cases originate from the period prior to the legalisation of assisted dying. Currently, there are recommendations for the medications that should be used that may have a reduced rate of complications.¹³⁶

4.4.2 Predictions of survival

The Oregon Model differs from other models for legalised assisted dying through its requirement that the patient have a maximum of six months left to live according to a “reasonable medical judgment.”¹³⁷ In a questionnaire sent to all physicians in Oregon prior to the anticipated legalisation on self-administered assisted dying in 1997, almost half of those who responded expressed doubt as to

¹³⁵ Health Canada 2017.

¹³⁶ The study is referenced in Emanuel et al. 2016.

¹³⁷ In Switzerland and the Benelux countries, there are no requirements of terminal illness at all, whereas Canada only requires death to be “reasonably foreseeable” without any exact time limit, see Chapter 3.

their ability to predict whether a patient has less than six months left to live.¹³⁸ A year after the law was implemented, 38 per cent of the physicians who said they were willing to prescribe medication for assisted dying felt “not at all” or “only a little” sure of their ability to determine whether a patient has less than six months left.¹³⁹

The median period of time in Oregon from the first oral request for self-administered assisted dying until death is less than two months (1998–2016). But, public statistics show that each year there are patients who receive prescriptions for self-administered assisted dying who live for longer than six months after their request. The longest interval was a patient who died almost three years after their request. A ten-year follow-up of the law showed that, of the 546 patients who received a prescription for self-administered assisted dying during the period between 1998 and 2007, 17 of them (3 per cent) lived for more than six months after the prescription was issued.¹⁴⁰ Statistics from the Washington health authorities show that approximately 90 per cent of patients die within 25 weeks of the initial request.

The fact that a small proportion of the patients live longer than six months is actually said to be due to the difficulty in providing exact predictions (rather than disregard for the terminal illness criteria; see the next subsection). Studies confirm that physicians have difficulty in accurately predicting how long, for example, a terminally ill cancer patient has left to live. The tendency, however, is to systematically overestimate the anticipated survival period, not to underestimate it.¹⁴¹

4.4.3 Assisted dying outside the regulations

Oregon and Washington

According to studies, there were cases of assisted dying before it was legalised both in Oregon and in Washington (from Oregon

¹³⁸ Lee et al. 1996.

¹³⁹ Ganzini et al. 2001.

¹⁴⁰ Hedberg et al. 2009.

¹⁴¹ Glare et al. 2003. The studies in this overview related to patients who generally had a life expectancy of less than six months.

there is data relating to self-administered assisted dying; from Washington there is data relating to self-administered assisted dying and euthanasia).¹⁴² Unlike the Netherlands, where illegal assisted dying is identified via the recurrent death certificate studies, there is very little data relating to potential cases of illegal assisted dying in Oregon and Washington since the legalisation. The study among relatives of 1,400 deceased Oregon residents found no cases of non-reported self-administered assisted dying.¹⁴³ One limitation here is that the relatives were questioned, rather than the physicians, where the former were perhaps not in possession of all the information. In a comment on the study, however, it was pointed out that the fact that there are regulations can make physicians less inclined to risk committing an illegal act, while at the same time, time limitations and other legal requirements create obstacles, for example, for anyone making a request too late.¹⁴⁴

With regard to the question of whether self-administered assisted dying, contravening the regulations, is administered to people with disabilities and the chronically ill, the authors of a study that investigated the situation for vulnerable groups in Oregon and the Netherlands point out that virtually all terminally ill patients suffer from some form of chronic illness. The majority also have some level of disability.¹⁴⁵ The crucial question is whether non-terminal patients with chronic illnesses are also granted assisted dying. When the study was carried out, there was no data relating to whether self-administered assisted dying would have been granted to any patient in Oregon who had not been deemed, by two physicians, to have a maximum life expectancy of six months, a criteria that still applies (the aforementioned lack of data relating to potential cases of illegal assisted dying in Oregon should, however, be taken into consideration.)¹⁴⁶ At the same time, public statistics from Oregon show that there are cases of patients surviving for

¹⁴² Lee et al. 1996; Back et al. 1996.

¹⁴³ Tolle et al. 2004.

¹⁴⁴ Ganzini och Dobscha 2004.

¹⁴⁵ Battin et al. 2007.

¹⁴⁶ Up until 2016, a total of 22 cases in which regulations have not be followed have been reported to the Oregon Medical Board. The most common errors are incomplete forms, late reporting or errors in the witnessing of the request. In one case, there was no written request at all and in another, the 48-hour waiting period from written request to prescription was not observed. No cases have led to disciplinary action by the Oregon Medical Board. Source: Oregon Health Authority (n.d.).

longer than six months after they made their initial request. According to the authors of the study mentioned, this is more likely to reflect the difficulty in providing an exact life expectancy than disregard for the terminal illness criteria.

Other countries

The Dutch death certificate studies have shown a decrease over time in the number of patients who receive euthanasia without having made an explicit request, either at the time of their death or in the form of an advance healthcare directive. In 1990, this occurred in 0.8 per cent of all deaths, in 2015 in 0.3 per cent of deaths.

The duration by which the patient's life is shortened is deemed by the physicians as being shorter in these cases than in the cases where an explicit request has been made (in six out of seven cases, the life is deemed to have been shortened by a maximum of one week). In six of ten cases, the physician has discussed the procedure with the patient, even if a formal request was not made. But in one out of four cases, the physician has not discussed the procedure with either the patient, any relative or another physician.¹⁴⁷

As previously mentioned, according to the 2007 death certificate studies in Belgian Flanders, perhaps as many as half of all cases of euthanasia were, despite legal requirements, not reported to the national review committee. In the non-reported cases, it was significantly more common for there to have been no written request or consultation with a colleague, which in both cases is a violation of the regulations.¹⁴⁸ No data about any changes to the level of reporting since then has been found. The most recent death certificate study (2013), however, shows that the proportion of cases where there has been both an oral and a written request and where a medical colleague has been consulted has increased. According to the authors of the study, this suggests that physicians have begun applying the criteria for assisted dying more strictly.¹⁴⁹

¹⁴⁷ This data comes from the 2010 death certificate studies, refer to Onwuteaka-Philipsen et al. 2012.

¹⁴⁸ Smets et al. 2010a.

¹⁴⁹ Chambaere et al. 2015.

The death certificate studies in Flanders also show that the proportion of deaths that were hastened without the explicit request of the patient has decreased. The proportion was 3.2 per cent in 2001 (before the law was implemented), 1.8 per cent in 2007 and 1.7 per cent in 2013.¹⁵⁰

In Switzerland, according to a study, the proportion of cases where death was hastened without the explicit request of the patient has increased from 0.5 per cent of all deaths in 2001 to 0.8 per cent in 2013 (this change has not been statistically confirmed). This study also shows that there are cases in which Swiss physicians perform euthanasia (i.e. end the patient's life at their explicit request) despite this not being permitted in Switzerland. In 2013, euthanasia accounted for 0.3 per cent of deaths.¹⁵¹

When it comes to intentionally hastened death without the explicit request of the patient, it should be noted that there are also cases of this in countries that do not permit assisted dying. In an extensive study from 2001–2002, physicians in six European countries were asked how common it was for them to perform that kind of procedure. According to the responses, this occurred in 0.6 per cent of deaths in the Netherlands and in 0.4 per cent of the cases in Switzerland. In Denmark, Sweden and Italy, this occurred in 0.7 per cent, 0.2 per cent and 0.1 per cent of the cases respectively, whereas the figure in Belgium, which legalised euthanasia during this particular period, was 1.5 per cent.¹⁵²

4.5 Depressed patients

Depression is common among patients at the end of life. Some research findings suggest there is a correlation between depression and the demand for assisted dying, both in Oregon and the Netherlands. However, the correlation with hopelessness is stronger.

¹⁵⁰ Chambaere et al. 2015.

¹⁵¹ Bosshard et al. 2016.

¹⁵² van der Heide et al. 2003. In the study, individual cases of self-administered assisted dying and euthanasia were reported from Denmark (where this is not permitted) but not from Sweden.

There are cases of depressed patients receiving assisted dying, but it is unclear to what extent depression influenced their decision-making capacity.

A number of studies have shown that depression is a common condition among terminally ill patients (according to a systematic review, the median is between 15 and 29 per cent of the patients, depending on the diagnostic method.)¹⁵³ There is also a correlation between depression and the wish to hasten death among patients at the end of life, a correlation that, according to some studies, is stronger than that for physical symptoms.¹⁵⁴ Based on this information, it has been claimed that a large proportion of the patients who request assisted dying are, in fact, depressed and it is this which is the basis for their request.¹⁵⁵

4.5.1 The correlation between depression and a wish for assisted dying

Oregon and Washington

In a couple of studies, patients in Oregon and their relatives were asked about the reasons for requesting self-administered assisted dying. When the respondents were asked to rank on a scale of one to five how important a variety of possible reasons were, a depressed mood was ranked as an unimportant factor (median one).¹⁵⁶ Nurses in palliative care who have looked after a patient who ended their life through self-administered assisted dying also classed depression as a less important factor underlying the patient's decision (median two).¹⁵⁷ In contrast to this, the aforementioned case-control study from 2015 (Subsection 4.3.4), in which the researchers themselves assessed the patients for clinical depression, showed that the level of depression was significantly higher

¹⁵³ Hotopf et al. 2002.

¹⁵⁴ Wilson et al. 2007; Chochinov et al. 1995; Blank et al. 2001; Breitbart et al. 2000; Emanuel, Fairclough and Emanuel 2000; Chochinov et al. 2005.

¹⁵⁵ Vachon 2004; Emanuel 2005.

¹⁵⁶ Ganzini, Goy and Dobscha 2008a; Ganzini, Goy and Dobscha. 2009.

¹⁵⁷ Ganzini et al. 2002. Among those patients who requested but were not granted self-administered assisted dying, however, depression was a slightly more important factor, according to the nurses.

among the patients who demanded self-administered assisted dying than among those who did not.¹⁵⁸

Hopelessness (pessimism about the future) can be one of the symptoms of depression. For someone with a terminal illness, however, the situation may seem hopeless without their fulfilling the criteria for clinical depression. Several studies suggest that hopelessness is more strongly linked to an interest in self-administered assisted dying than depression is. The aforementioned study of motor neurone disease patients in Oregon and Washington (see Subsection 4.3.3), which was carried out before self-administered assisted dying was legalised in Oregon, showed that hopelessness was more common among those patients who said they would request a prescription for self-administered assisted dying if it were legal. Nevertheless, depression was no more common in that group than among the patients who had not shown an interest in self-administered assisted dying.¹⁵⁹ When the relatives were later asked whether the patients had discussed self-administered assisted dying during their final month, no correlation was found between the occurrence of such a discussion and a depressed state of mind in the earlier stage. There was, however, a correlation to a previously expressed hopelessness.¹⁶⁰ The study from 2015, which showed that the level of depression was higher among those patients who demanded self-administered assisted dying, found an even stronger correlation between the demand for self-administered assisted dying and hopelessness.¹⁶¹

It should be noted that the studies of terminally ill patients mentioned at the beginning of this section relate to an interest in hastening death. The step from expressing an interest in hastening death to actually making a request for self-administered assisted dying appears to be a big one. In the study involving the relatives of 1,400 deceased Oregon residents who died between 2000 and 2002, the relatives said that 236 patients (17 per cent) had at some point considered self-administered assisted dying. But only 25 pa-

¹⁵⁸ Smith et al. 2015.

¹⁵⁹ Ganzini, Silveira and Johnston 2002.

¹⁶⁰ Smith et al. 2015. With regard to hopelessness as an independent explanation of an interest in hastening death, refer also to Chochinov et al. 1998; Breitbart et al. 2000.

¹⁶¹ Tolle et al. 2004.

tients (2 per cent) made a formal request.¹⁶² Another study, carried out between 1998 and 2001, longitudinally followed 42 cancer patients who had shown some degree of interest in self-administered assisted dying at the start of the study. The study showed that the interest in self-administered assisted dying varied over time, where an increase in depression and hopelessness increased the interest (other factors that increased the interest were declining functional status, deteriorating quality of life, decreasing satisfaction with medical care, increasing pain and other suffering, increasing sense of being a burden to the family and increasing social support).¹⁶³ But, despite the fact that 19 of the 42 patients at some point during the period (up to two years) the patients were being monitored, demonstrated a strong interest in self-administered assisted dying, only two of them made a formal request.¹⁶⁴ The patients who were being monitored were part of a larger group of 161 patients who were evaluated for depression and hopelessness at the start of the study. A strong statistical correlation was discovered between the degree of interest in self-administered assisted dying and hopelessness, poor quality of life and low satisfaction with the quality of care (only the latter variable, however, was independent in a multi-variable analysis). The correlation with depression, suffering and the feeling of being a burden on the family was weaker yet significant.

Other countries

A systematic review from 2011 reviewed all studies in Oregon and the Netherlands that had investigated the correlation between depression and requested/granted assisted dying.¹⁶⁵ Among the studies that investigated whether depression was more common among patients who request assisted dying than among other patients, all three studies in the Netherlands that were considered to be of a high quality showed that depression was more common among

¹⁶² A changing interest in assisted dying over time also appeared in Emanuel et al. 2000. Of 100 patients who seriously considered assisted dying, half of those who were still alive had changed their minds at a follow-up two to six months later.

¹⁶³ Ganzini et al. 2006.

¹⁶⁴ Levene and Parker 2011.

¹⁶⁵ van der Lee et al. 2005.

patients who request assisted dying (the frequency of depression, which was measured using different methods, varied between 8 and 47 per cent). Only in one of the studies, however, the one deemed to be of the highest quality, were the differences considered to be significant. In that study, 44 per cent (14 of 32) of the patients who were considered to be depressed requested assisted dying, whereas 15 per cent (16 of 105) of the patients who were not considered to be depressed did. The relative risk of requesting assisted dying was four times greater among the depressed patients than among the patients who were not depressed. The majority of those who requested assisted dying were, however, not depressed.

4.5.2 Are depressed patients identified?

Oregon and Washington

Neither in the Oregon model nor in any other model for assisted dying is the presence of depression something that in itself disqualifies someone from assisted dying. Depression can, however, have a negative impact on judgement when it comes to assessing the situation and possible future outcomes.¹⁶⁶ Given depression's potential effect on judgement, the regulations in the countries and states that have introduced assisted dying recommend extra vigilance with regard to patients suspected of suffering from depression (see Chapter 3). One problem highlighted in some studies is that physicians without specialist training in psychiatry may have trouble recognising depression, particularly in the terminally ill when some of the symptoms typical to depression can also be caused by the physical illness.¹⁶⁷

In Oregon and Washington, a physician who suspects that a patient requesting self-administered assisted dying is suffering from a psychiatric disorder that affects their judgement should refer them to a psychiatrist or psychologist for an assessment. No medications may be prescribed until the psychiatrist/psychologist confirms that the patient's judgement is not impaired due to a psychiatric disorder. According to the health authorities' annual reports, 4 and 5

¹⁶⁶ Levene and Parker 2011.

¹⁶⁷ Levene and Parker 2011.

percent respectively of the patients who died from self-administered assisted dying in Oregon and Washington in 2016 were referred for psychiatric or psychological assessment. In Oregon, the proportion being referred has decreased over time. During the first three years after legalisation, one patient in four was assessed by a psychiatrist or a psychologist.

In a survey that was carried out prior to legalisation, in which almost 2,800 physicians in Oregon took part, 28 per cent said that they were not sure whether they would recognise depression in a patient who had requested a prescription for self-administered assisted dying.¹⁶⁸ When, in a study carried out a couple of years after the introduction, 144 physicians in Oregon who had received requests for self-administered assisted dying were asked, 20 per cent said that the patient had symptoms of depression. 93 per cent of the patients were, nevertheless, considered to be capable of making decisions about their care. None of the patients who were deemed to have depressive symptoms had received a prescription for self-administered assisted dying.¹⁶⁹

In a study in Oregon from 2008 involving 58 patients who had requested self-administered assisted dying, the researchers themselves assessed the patients for depression.¹⁷⁰ Of the 58 patients, 15 (26 per cent) met the criteria for depression (six of them felt that the depressive state, to a certain extent at least, affected their wish to hasten death). Of the 15, twelve were later denied self-administered assisted dying, but the remaining three were granted it and died through self-administered assisted dying. In two of the cases it was unclear whether the patient was subsequently assessed and received treatment for depression, but in one case, the patient received treatment for depression. When the patient ended her life, her condition was in remission.

Other countries

Of the studies from the Netherlands that were reviewed in the systematic review from 2011, all of the studies deemed to be of a

¹⁶⁸ Lee et al. 1996.

¹⁶⁹ Ganzini et al. 2000.

¹⁷⁰ Ganzini, Goy and Dobscha 2008b.

high quality (four in total) showed that the incidence of depression was significantly lower among those patients who were granted assisted dying (2–10 per cent) than among those who were denied assisted dying (12–39 per cent). The frequency of depression in patients who received assisted dying was, according to several of the studies, at the same level as in patients with the same diagnosis who had not requested assisted dying. But, according to all of the studies, there were cases of depressed patients receiving assisted dying.¹⁷¹

4.5.3 Assessing effects on judgement

Oregon and Washington

Legislation in Oregon and Washington does not prevent a depressed patient from receiving assisted dying, provided the illness does not affect the patient's judgement.¹⁷² If there are suspicions that a patient's judgement has been impaired by psychiatric disorder, the physician should refer to the patient to a psychiatrist or a psychologist. In a study in Oregon that was carried out before the legalisation on assisted dying, 321 psychiatrists in Oregon were asked how they rated their ability with a single evaluation to assess whether any psychiatric disorder affects the patient's judgement (the question related specifically to terminally ill patients). 51 per cent were not at all confident that they would be able to make such an assessment and only 6 per cent were very confident. There was a significant correlation between how confident a person is about making the assessment and how positive they are about self-administered assisted dying, but even among the two thirds who were in favour of self-administered assisted dying, a large number were uncertain that they would be able to determine a patient's ability to make a sound judgement with a single evaluation. The vast majority, however, regardless of whether they were in favour

¹⁷¹ Levene and Parker 2011.

¹⁷² It is unclear how the criteria for an unimpaired judgement relates to the criteria for the patient being capable, i.e. having the ability to make and communicate decisions about their own healthcare. The criteria for an unimpaired judgement does not appear to be general in any case. The law states that judgement may not be impaired due to a psychiatric disorder, but does not seem to rule out its being impaired for other reasons.

of or opposed to self-administered assisted dying, were very or somewhat confident that they would be able to make the assessment if they already knew the patient.¹⁷³

Other countries

Unlike in Oregon and Washington, psychological, non-terminal illnesses can qualify a patient for assisted dying in the Benelux countries if the suffering is deemed to be unbearable. In Belgium, psychiatric expertise is involved in seven out of ten cases where assisted dying is granted to patients without a terminal illness.¹⁷⁴ In the Netherlands, an independent psychiatric assessment is carried out in nine out of ten cases in which assisted dying is granted to patients for psychiatric disorders.¹⁷⁵

4.6 Assisted dying and palliative care

In Oregon and Washington, the number of patients with access to palliative care at the time of their death is increasing, both when it comes to all patients as well as those who die through self-administered assisted dying. Access to palliative care is at the same level as in the rest of the US. In other countries where assisted dying is permitted, expansion of palliative care has also continued after legalisation.

There are reports that many patients who receive a substantial amount of care, such as palliative care, change their minds and no longer want assisted dying.

Palliative care in Oregon and Washington tends to maintain a certain distance from the practice of self-administered assisted dying, although there is great deal of support for the principle of not abandoning the patient. Advocates of palliative care in Belgium believe, however, that assisted dying can be seen as part of the palliative care.

¹⁷³ Ganzini et al. 1996.

¹⁷⁴ Commission fédérale de contrôle et d'évaluation de l'euthanasie. 2016.

¹⁷⁵ Kim, De Vries and Peteet 2016.

4.6.1 Access to palliative care

Oregon and Washington

In the US, just as in many other parts of the world, the proportion of patients at the end of life with access to palliative care is increasing (in the US, palliative care is generally delivered in the home.)¹⁷⁶ In 2015, in the whole of the US, 83 per cent of those who died were registered with Medicare, the health insurance system for the elderly and people with disabilities. Of these, 47 per cent had access to palliative care when they died. In Oregon, 87 per cent of those who died in 2015 were registered with Medicare, of whom 52 per cent were receiving palliative care. In Washington, 84 per cent of those who died were registered with Medicare, of whom 42 per cent were receiving palliative care.¹⁷⁷

In the extensive 1999 survey responded to by just over 2,600 physicians in Oregon, 30 per cent said that they referred more patients for palliative care in 1999, two years after the introduction of the Death with Dignity Act, than in 1994, whereas 3 per cent said that they referred fewer (according to the authors, this reflected an overall trend in the US and could not necessarily be correlated with the Death with Dignity Act). Every third physician felt that access to palliative care had increased, whereas 1 per cent felt that access had decreased. In fact, according to the authors, access had remained constant and the probable explanation was that awareness of palliative care as an alternative had increased. Among those who had dealt with at least one terminally ill patient in the previous year, 76 per cent said that they had acquired more knowledge about pain relief, 69 per cent that they had acquired more knowledge about psychiatric disorders and 79 per cent that they had become more confident about prescribing pain medications.¹⁷⁸

Other countries

In connection with the legalisation on assisted dying, both Belgium and Luxembourg adopted laws that guarantee dying patients the

¹⁷⁶ National Hospice and Palliative Care Organization 2016.

¹⁷⁷ Oregon Hospice & Palliative Care Association 2017a.

¹⁷⁸ Ganzini et al. 2001.

right to palliative care. An article from 2015 describes how the available palliative care options have been developed since assisted dying was (formally) legalised in Belgium and the Netherlands in 2002, and in Luxembourg in 2009.¹⁷⁹ The data reported comes from the 2007 and 2013 edition respectively of the “atlas” of palliative care in Europe, issued by the European Association of Palliative Care (EAPC). A value for the overall availability of palliative care resources has been calculated for each country (palliative units/teams in hospitals, palliative home healthcare teams and special clinics or wards are all counted as palliative resources in this context). At both measurement points (2005 and 2012 respectively), the Benelux countries, together with Iceland, the UK, Sweden and Ireland, had the highest scores in Europe. Belgium, which was in second place in 2005, maintained a steady availability of 18 resources per million inhabitants (finance, however, doubled during the period). Luxembourg and the Netherlands had, however, expanded their availability considerably between 2005 and 2012 (in Luxembourg, availability rose from 8.8 to 19.1 resources per million inhabitants and in the Netherlands from 8.4 to 15.3 resources per million inhabitants). One limitation of this data is that it does not tell us how many patients actually make use of the resources. Furthermore, the authors also point out that, even if the numbers do not suggest any short-term negative impacts of legalised assisted dying on palliative care, a more long-term impact cannot be ruled out.

In a 2009 study, 3,000 Belgian physicians were asked for their opinion on the euthanasia law. Of the just over 900 who responded, 62 per cent of whom were GPs, 72 per cent did not agree with the statement that the law was preventing palliative care from expanding. Palliative care training did not affect the physicians’ fundamental attitude to euthanasia, but physicians with this kind of training were less inclined than other physicians to agree with the statement that the law was preventing palliative care from expanding, while at the same time they emphasized more strongly the need for societal control over the practice of assisted dying (the differences were significant).¹⁸⁰

¹⁷⁹ Chambaere and Bernheim 2015.

¹⁸⁰ Smets et al. 2011.

4.6.2 The relationship between demand for assisted dying and availability of palliative care

Oregon and Washington

Of those patients who die through self-administered assisted dying in Oregon and Washington, according to the health authorities' annual reports, a large number are registered for palliative care when they die. In Oregon, the proportion has risen from 76 per cent in 1998–1999 to 89 per cent in 2016, and in Washington from 72 per cent in 2009 to 77 per cent in 2016. In the initial reports from the health authorities in Oregon during the first few years, there is also data relating to the number of people who were registered for palliative care when they made their first request for assisted dying (52 per cent).

It is not clear from recent public statistics how many of those without access to palliative care were offered it but declined, but according to data from Oregon for the years 1998–2003, all patients who died through self-administered assisted dying were offered palliative care. Patients in Washington who requested self-administered assisted dying and their relatives did not mention a lack of access to palliative or any other care as a motive when they were asked in a study.¹⁸¹

At the same time, a survey from 1999 of 2,600 physicians in Oregon found that patients who had requested self-administered assisted dying and thereafter received a substantial medical intervention (symptom management; referral to a hospice program; mental health, social-work, chaplaincy or palliative care consultation; or anti-depressive treatment) were more inclined to change their minds about self-administered assisted dying compared to patients who had not received this type of assistance. Of 67 patients who had received this type of assistance, 31 (46 per cent) changed their minds and did not want self-administered assisted dying, whereas only 11 out of 73 patients (15 per cent) who had not received this type of assistance changed their minds. Of the patients who received a prescription for self-administered assisted dying without having received any substantial medical intervention after their

¹⁸¹ Pearlman et al. 2005.

request, more than 60 per cent (11 out of 18) were already registered for palliative care.¹⁸²

It should also be mentioned here that the physicians in the aforementioned in-depth survey (Subsection 4.3.4) said that in the (relatively few) cases where patients were willing to consider alternatives to assisted dying, it was when the physician could address the patients' symptoms or future fears and the patient was reassured that the physician would be available throughout the course of the illness.¹⁸³

It should also be noted that experiencing a low quality of care was one of the factors that affected the interest in self-administered assisted dying in the aforementioned study of patients with advanced cancer (Subsection 4.5.1). The authors believe that this may suggest that earlier access to palliative care could reduce the demand for self-administered assisted dying.¹⁸⁴

Other countries

With regard to the question as to whether patients choose assisted dying for want of access to palliative care, the latest death certificate study in Belgium (2013) shows that 74 per cent of the patients who died through euthanasia or self-administered assisted dying had received palliative care.¹⁸⁵ A study in the Netherlands, in which the researchers reviewed all deaths over a four-month period in 2010, found a significant positive correlation between death by euthanasia and the fact that a palliative care or pain specialist had been involved in the final month.¹⁸⁶ The same pattern could be seen in a study in Belgium, but the correlation there was not significant.¹⁸⁷ In Belgium, however, the proportion of euthanasia cases where a palliative team was consulted in connection with the patient's request rose from 34 to 39 per cent between 2003 and 2013.¹⁸⁸

¹⁸² Ganzini et al. 2000.

¹⁸³ Ganzini et al. 2006.

¹⁸⁴ Ganzini et al. 2006.

¹⁸⁵ Chambaere et al. 2015.

¹⁸⁶ Brinkman-Stoppelenburg, Owuteaka-Philipsen and van der Heide 2015.

¹⁸⁷ Van den Block et al. 2009.

¹⁸⁸ Dierickx et al. 2016.

In a study carried out in connection with the 2001 Dutch death certificate study, one in three Dutch physicians agreed that access to adequate palliative care would lead to euthanasia becoming redundant, whereas six out of ten did not agree. As this study was carried out before the major expansion of palliative care in the Netherlands (see previous subsection), it is difficult to know whether the answer would be the same today.¹⁸⁹

4.6.3 When assisted dying meets palliative care

Oregon and Washington

The organisation for palliative care in Oregon, the Oregon Hospice & Palliative Care Association, supports patients' right to choose between various options at the end of life, including self-administered assisted dying. It is felt that hospices are uniquely qualified to address the needs of dying patients and that Oregonians should not have to choose between self-administered assisted dying and palliative care.¹⁹⁰ Its sister organisation in Washington, the Washington State Hospice and Palliative Care Organization, has no specific stance when it comes to self-administered assisted dying.¹⁹¹ The national organisation for palliative care in the US, the National Hospice and Palliative Care Organization, does not support the legalisation of self-administered assisted dying¹⁹².

A couple of studies have investigated the degree to which hospices in Oregon and Washington respectively are prepared to participate in self-administered assisted dying. The studies were based on policy documents, guidelines and staff education material from the hospices. All of the hospices stated that they offered the same care regardless of whether a patient had requested or intended to request self-administered assisted dying.¹⁹³ According to the authors, self-administered assisted dying nevertheless presents palliative care providers with particular challenges when it comes to combining various fundamental values that have traditionally char-

¹⁸⁹ Georges et al. 2006.

¹⁹⁰ Oregon Hospice & Palliative Care Association 2017b.

¹⁹¹ Campbell and Black 2014.

¹⁹² National Hospice and Palliative Care Organization (n.d.).

¹⁹³ Campbell and Cox 2012; Campbell and Black 2014.

acterised palliative care, such as respect for the patient's self-determination, respect for the physician-patient relationship, the idea that life should be neither hastened nor prolonged, the principle of not abandoning the patient, and the goal of improving quality of life at the end of life. A review of the various hospices' policy documentation showed that the majority, to a greater or lesser extent, maintained a certain distance from self-administered assisted dying. Virtually all hospices were clear about the fact that they ruled out direct involvement through, for example, supplying medication for self-administered assisted dying (which only physicians and pharmacists are permitted to do). A small proportion of the hospices in Oregon chose to limit their involvement as far as possible and not even supply patients with information about the Death with Dignity Act. The majority, however, viewed basic information about the law and its criteria as being part of their commitment to help patients make an informed decision about their care. Some hospices permitted the staff to have a "neutral" discussion with the patient about the various options. A small proportion chose to be involved in the process as far as possible within the confines of the law by informing the patient's physician if a patient raises the issue, or refer the patient to organisations who can help them find a physician willing to participate.

Most of the hospices in both Oregon and Washington prohibited their staff from attending, while on duty, when the patient takes the medication. However, this does not seem to have been mainly a matter of principle, but rather based on a concern that the operation might be seen to be encouraging self-administered assisted dying or having some responsibility for ensuring that the procedure occurs without complications.

The policy that palliative care providers should not abandon a patient who requests self-administered assisted dying seems to be widely supported among the staff. A 2001 study in Oregon investigated the experiences of and attitudes to self-administered assisted dying among palliative care staff (nurses and social workers).¹⁹⁴ 95 per cent of the just under 400 respondents felt that the caregiver should continue to look after a patient who requested self-administered assisted dying. The principle of not abandoning a

¹⁹⁴ Miller et al. 2004.

patient applies to most of the staff also on a personal level. Despite the fact that a third of the nurses, the largest group of respondents, were opposed to self-administered assisted dying, only 12 per cent would transfer care for a patient who had received a prescription for self-administered assisted dying to another hospice clinician.

The study also revealed that 45 per cent of the respondents had at some point cared for a patient who had explicitly requested self-administered assisted dying, and almost two thirds had discussed self-administered assisted dying with at least one patient in the past year (15 per cent had initiated this kind of conversation themselves). 22 per cent had experienced this kind of conversation as uncomfortable. Of those who had cared for a patient who had shown an interest in self-administered assisted dying in the past year (55 per cent), a third had attempted to facilitate the patient access self-administered assisted dying. The patients would often feel more secure knowing the individual employee or organisation's attitude to self-administered assisted dying, but 13 per cent of the respondents reported that patients became upset by the organisation's attitude. The authors draw two conclusions from the study results. The first is that the people who work with palliative care do not consider the principles of palliative care and those of self-administered assisted dying to be mutually exclusive, as they feel that these patients should remain with the operation. The second conclusion is that, if self-administered assisted dying is actually introduced, it will be practically impossible to entirely separate self-administered assisted dying from palliative care, as it is within the realm of palliative care that questions about self-administered assisted dying arise naturally.

Other countries

In 2003, the Federation of Palliative Care Flanders became the first professional organisation for palliative medicine to endorse the idea that euthanasia and palliative care are not conflicting practices and that euthanasia can be part of palliative care treatment.¹⁹⁵ In an article from 2013, representatives of the association describe the

¹⁹⁵ Bernheim et al. 2008.

shift from a previously disapproving attitude.¹⁹⁶ After the legalisation of euthanasia in 2002, there was a situation where patients who were denied euthanasia within the palliative care system instead turned to external physicians who did not know the patients as well. To accept dealing with euthanasia to avoid having to abandon the patients was seen, in that situation, as a “lesser evil”. Eventually the organisation came to the conclusion that palliative care teams have skills that make them better equipped than many other caregivers to deal with the complex issues associated with euthanasia, such as intractable symptoms, undiagnosed depression, feelings of guilt and pressure from relatives. Above all, they have the knowledge about the palliative options that the law requires the patients to be given.

Other benefits of having a clear link with palliative care, according to the authors, are that it makes it easier to resist requirements that euthanasia be granted to an increasing number of patient groups and can prevent the legal requirements for assisted dying from being seen as in themselves sufficient for good care. A strong link with palliative care can also, according to the authors, prevent euthanasia from contributing to death being “instrumentalised” and the idea spreading that death in itself is undignified. This “embedding” of euthanasia within palliative care being promoted by the Flemish organisation is, however, controversial. The European Association of Palliative Care (EAPC) believes that there are both ethical and medical reasons that speak against euthanasia and self-administered assisted dying, and that assisted dying should not be included into the practice of palliative care.¹⁹⁷

4.7 Suicide

One hypothesis that is sometimes put forward is that assisted dying can reduce the number of suicides, in particular in the older segment of the population where some suicides are thought to be the result of people wanting to avoid the suffering associated with dying from certain serious illnesses.

¹⁹⁶ Vanden Berghe et al. 2013.

¹⁹⁷ Radbruch et al. 2016.

Determining the impact assisted dying has had on the number of suicides in a country where assisted dying has been introduced is difficult. Suicide is a complex phenomenon that is influenced by factors that do not necessarily have anything to do with access to assisted dying. Other factors could counteract or reinforce the possible impact of the introduction of assisted dying. This means that a drop in frequency after the introduction of self-administered assisted dying does not necessarily mean that self-administered assisted dying is the cause. On the contrary, the decrease may have been even greater without self-administered assisted dying. Conversely, an increase is not evidence that self-administered assisted dying leads to more suicides.

One way to trace the possible effects of introducing self-administered assisted dying could be to try to see whether the introduction has been associated with changes in the overall suicide trend. A 2015 study analysed suicide statistics from Oregon, Washington and Montana, states which at different times have legalised or decriminalised assisted dying, to ascertain whether there had been any changes after introduction.¹⁹⁸ In the statistical analysis, compensation was made for the general trend in the number of suicides in the US (which is increasing), differences in various factors that coincide with the suicide rate (for example, degree of religiousness and ethnic composition) as well as state-specific trends (Montana, for example, had a sharply rising suicide rate even before self-administered assisted dying was decriminalised).

According to the study, if cases of self-administered assisted dying are included in the suicide statistics, the introduction of self-administered assisted dying led to a 6.3 per cent rise in suicides in those states. This result was statistically significant. This can be viewed in light of the fact that, since it was introduced, self-administered assisted dying accounted for 7.4 per cent of all suicides in Oregon and 8.1 per cent of all suicides in Washington. If you discount the deaths from self-administered assisted dying, the increase was 1.1 percent, which was not statistically significant. Among people aged 65 and above, suicide rose by 14.5 per cent when cases of self-administered assisted dying were included. When deaths from self-administered assisted dying were discount-

¹⁹⁸ Jones and Paton 2015.

ed, however, there was a 4.5 per cent decrease among the elderly, but this change was not significant. The results of the survey should, according to the authors of the study, be interpreted with some caution, as there may be unknown factors that influence the suicide rate and that could not be compensated for. One should also be aware that there are no statistics for cases of self-administered assisted dying in Montana, so these cannot be discounted from the total number of suicides.

4.8 Experiences of and attitudes to self-administered assisted dying

When the circumstances surrounding dying were studied in Oregon, no differences were seen between patients who had requested and not requested self-administered assisted dying with regard to symptom management, relationships with relatives and preparation for death.

According to studies from Oregon, the grieving process for relatives is not affected by the fact that a patient has died through self-administered assisted dying. They are, however, more prepared for their relative's death than the relatives of other patients.

The majority of physicians in Oregon supported the Death with Dignity Act when it was introduced. Fewer, however, were willing to actually participate in self-administered assisted dying. The physicians who participated report mixed emotions: there is a heavy emotional burden, but they generally do not regret their involvement.

Support for the Death with Dignity Act among the people of Oregon remains strong. No data relating to how the law is perceived among vulnerable groups has been found.

4.8.1 Patients

Oregon and Washington

In a case-control study from Oregon, relatives were asked to evaluate the final period of life from the patient's perspective with regard to symptom management, relationships with relatives, preparation and concern/serenity about their death.¹⁹⁹ 84 relatives of patients who had requested self-administered assisted dying took part in the study (some of the patients had been denied self-administered assisted dying, some had been granted but not died through self-administered assisted dying and some had been granted and died through self-administered assisted dying). The control group consisted of 63 relatives of patients with the same illnesses who had never requested self-administered assisted dying. When it comes to overall evaluation of the final period of life, there was no significant difference between those patients who had requested and those who had not requested self-administered assisted dying. The quality of the moment of death, however, was higher among the patients who had used their prescription for self-administered assisted dying than among those who had received a prescription but not used it. Patients who had received a prescription for self-administered assisted dying had better symptom management than other patients and had said farewell to their loved ones to a greater extent. But, patients who had requested but not received access to self-administered assisted dying had, according to their relatives, a tendency to worry more about being a strain on their relatives. The results of this study should be interpreted with a degree of caution as the recruitment method means the possibility cannot be ruled out that relatives with a positive experience of self-administered assisted dying may have been overrepresented.

Other countries

In a study from the Netherlands, in-depth interviews were carried out with 87 relatives of patients who had died through assisted

¹⁹⁹ Smith et al. 2011.

dying (the participation rate was 90 per cent).²⁰⁰ 92 per cent of those interviewed said that assisted dying had clearly contributed to the quality of the end of life of the patient and 7 per cent said that it had contributed to some degree. Among the aspects raised were that further suffering had been avoided, that the patient's wishes had been respected, that the patient's dignity had been preserved and that unbearable suffering had been alleviated. All or almost all of the patients had been ready to die, had said farewell to their relatives and had died peacefully.

4.8.2 Relatives

Oregon and Washington

According to the regulations in Oregon and Washington, the patient's physician should recommend that a patient who requests self-administered assisted dying inform their relatives about it. According to statistics from the health authorities in Oregon, 93 per cent of the 1,127 patients in Oregon who died through self-administered assisted dying between 1998 and 2016 followed that recommendation. A few per cent had no family to inform, whereas 5 per cent chose not to inform their family. In Washington, 94 per cent of patients in 2016 informed their family.

Suicide often has profound effects on the relatives, with shame, guilt, stigmatisation and rejection being common reactions.²⁰¹ The aforementioned case-control study of relatives in Oregon therefore studied whether the relatives of the patients who had requested self-administered assisted dying had experienced a more difficult grieving process than the relatives of those patients who had died from their underlying illness.²⁰² The study found no statistically significant differences with regard to the presence of depression or prolonged grief disorder between the two groups. Nor was it more common in any one of the groups for someone to receive psychiatric care afterwards. Nor could any such differences be noted between whether the relative had only requested self-administered

²⁰⁰ Georges et al. 2007.

²⁰¹ Sveen and Walby 2008.

²⁰² Ganzini et al. 2009.

assisted dying or had also died through self-administered assisted dying.

Of the relatives of patients who had died through self-administered assisted dying (which constituted 36 of 95 relatives in the case group), the vast majority (34) felt included in the patient's decision. There were no significant differences between the case and control groups with regard to how they experienced the opportunity to say farewell. However, the relatives of patients who had requested self-administered assisted dying were more prepared for the death of their relative, had accepted the fact of their relative's death to a greater extent and were less likely to endorse that they wanted more opportunities to care for their relative (all of these differences were significant). Relatives of people who had requested self-administered assisted dying, however, felt to a lesser extent that the relative's preferences for care at the end of life had been respected. This perception was particularly characteristic of relatives of patients who had requested but not been granted self-administered assisted dying.

These results, too, may have been tainted by the fact that a larger proportion of relatives with a positive attitude to self-administered assisted dying may have taken part in the study. The fact that relatives of patients who die through self-administered assisted dying are better prepared for the patient's death and find it easier to accept than other relatives is, however, a view that also the nurses in palliative care in Oregon (see Subsection 4.3.4) convey. 40 per cent of the nurses felt that the relatives of these patients were more prepared; 12 per cent that they were less prepared.²⁰³ Almost half of the nurses also said that relatives of patients who had died through self-administered assisted dying found, to a greater extent, positive meaning in caring for the patient than relatives of other patients, whereas 16 per cent said that the relatives found, to a lesser extent, positive meaning in caring for the patient. When it comes to the burden on the relatives of caring for the patient, there were more nurses who felt that these patients were less of a burden on their relatives than other patients (31 per cent) than who felt that they were more of a burden (11 per cent). Nevertheless, as was the case with other studies, the nurses said that concern

²⁰³ Ganzini et al. 2002.

of being a burden on relatives was one of the most important reasons why the patients requested self-administered assisted dying (see Subsection 4.3.3).

In the in-depth survey of physicians in Oregon with patients who had requested assisted dying (see Subsection 4.3.4), the physicians said that the patients were prepared to pursue their wish for assisted dying even in those cases where the relatives were opposed to it.²⁰⁴ This view conflicts with the picture that comes across in the study of nurses. In that study, there was a statistical correlation between the relatives' attitude to self-administered assisted dying reported by the nurses and the likelihood of a request being granted.²⁰⁵ This might suggest that support from the family could be important for completing the necessary process for access to self-administered assisted dying.

In connection with the longitudinal study that monitored patients with advanced cancer who had shown an interest in self-administered assisted dying, the relatives' attitude was also investigated. The relatives' religiousness increased the likelihood of opposition (14 per cent of the variation could be attributed to that factor) whereas the impact on their own health due to their relative's illness increased the likelihood of support for self-administered assisted dying (the factor explained 4 per cent of the variation).²⁰⁶

Other countries

An older case-control study from the Netherlands (of patients who had died between 1992 and 1999) showed that relatives of patients who died through euthanasia had significantly lower scores for traumatic grief than the relatives in the control group. The factor that explained most of the difference was that relatives of euthanasia patients had, to a greater extent, had the opportunity to say farewell to the deceased. According to the authors, another explanation could be more openness about the prognosis among eutha-

²⁰⁴ Ganzini et al. 2003b.

²⁰⁵ Ganzini 2003.

²⁰⁶ Ganzini, Beer and Brouns 2006.

nesia patients and their relatives, which may have led to a milder grieving process.²⁰⁷

4.8.3 Physicians

Oregon and Washington

In 1996, when it became clear that legalisation of self-administered assisted dying was a realistic possibility in Oregon, 60 per cent of the physicians in the state felt that self-administered assisted dying should be permitted in certain cases.²⁰⁸ Among A&E physicians and psychiatrists the support was even higher, almost 70 per cent.²⁰⁹

In the extensive survey of 4,000 physicians in Oregon that was carried out two years after the introduction, 51 per cent of the just over 2,600 physicians who responded said that they supported the law, 17 per cent said that they were neutral and 31 per cent said that they were opposed to the law. Three out of ten physicians agreed with the statement that the law was unethical, whereas six out of ten disputed this. 13 per cent had become more positive and 7 per cent had become more negative since 1994, when the first bill was proposed.²¹⁰ There is no data relating to changes in support among physicians in Oregon since then. Ever since the Death with Dignity Act was introduced, the Oregon Medical Association has maintained a neutral stance on self-administered assisted dying (in 2015 the Californian Medical Association followed suit, thereby becoming the second state association to break with the American Medical Association's dissociation from all forms of assisted dying).²¹¹

Although many physicians supported the law in principle, they were, at least in the beginning, more hesitant about actually participating in self-administered assisted dying. Two years after the introduction, only one in three were willing to prescribe medication

²⁰⁷ Swarte et al. 2003.

²⁰⁸ Lee et al. 1996.

²⁰⁹ Schmidt et al. 1996; Ganzini et al. 1996.

²¹⁰ Ganzini et al. 2001.

²¹¹ Ragan-Fore A, 2016; California Medical Association 2015. Since 2015, several other state medical associations have adopted a neutral stance.

for self-administered assisted dying, whereas just less than half were unwilling.²¹² At least during the first few years after the law was introduced, there seems to have been some concern among physicians about being stigmatised if they participated in self-administered assisted dying. Among the physicians who did not find self-administered assisted dying immoral, six out of ten nevertheless felt some concern at being labelled a “Kevorkian” if they prescribed medication for self-administered assisted dying.²¹³

Occasionally being asked whether you are potentially willing to participate in self-administered assisted dying (i.e. not a formal request) is something that physicians in Oregon have to expect. Just a couple of years after the law took effect, more than a third of the physicians had been asked those types of questions. One in five physicians had sensed that a patient felt more secure about their care after discovering the physician’s attitude to self-administered assisted dying. But, in some cases, the patients became upset when they learned that the physician had a different opinion to themselves, and it sometimes led to the patient choosing another physician. This happened to physicians who were opposed to self-administered assisted dying more than twice as often as physicians who supported it.²¹⁴

In the aforementioned in-depth survey of physicians in Oregon with patients who had requested self-administered assisted dying, the physicians were also asked about their attitude to self-administered assisted dying and how they were affected by meeting these patients.²¹⁵ Of the physicians who were willing to participate in self-administered assisted dying (21 of 35), many saw the procedure primarily as a clinical last resort, an option to take when all other treatment options had been exhausted. A smaller proportion saw self-administered assisted dying primarily as a matter of self-determination for the patient.

This study, too, revealed concern among physicians about how their reputation would be affected if they participated in self-administered assisted dying. There was also concern about the legal and practical aspects, in addition to the personal impact of partici-

²¹² Ganzini et al. 2001.

²¹³ Also refer to Chin et al. 1999.

²¹⁴ Ganzini et al. 2001.

²¹⁵ Dobscha et al. 2004.

pation.²¹⁶ Some argued that it was huge difference between being in favour of self-administered assisted dying as a matter of principle, and having a patient standing in front of you asking for it. For those physicians who were used to caring for the terminally ill, it was easier to deal with the requests for self-administered assisted dying, just as it was for the physicians who knew the patient well.

Not abandoning the patient was an important issue for both the physicians who granted and those who rejected requests for self-administered assisted dying. In the case of the latter, the patients were often referred to physicians who they thought would be more willing to prescribe medication. At the same time, the fact that the patients were often determined about what they wanted and did not want to discuss other options sometimes led to a feeling of failing as a physician.

The physicians' experience of participating in self-administered assisted dying is characterised by ambivalence. It felt like a huge emotional undertaking associated with a strong sense of duty. A number of physicians described a sense of relief when a patient died from other causes so that they did not have to prescribe any medication. When the patient actually died through self-administered assisted dying, most of them nevertheless said that it had been a quick and peaceful farewell. Most of the physicians did not afterwards regret their participation, but a few regretted that they had not communicated with the patient more and been more available. Despite not having changed their stance on the question of principle, among many of the physicians there was uncertainty about how they would react in future cases due to the emotional strain. On the other hand, many felt that the request for self-administered assisted dying had opened the way to discussions with the patient about important issues, and that the experience had helped them to become better at talking to patients about the end of their life.

Another thing that was clear was that the physicians who had participated in self-administered assisted dying refrained from telling their colleagues, partly due to their sensing opposition and

²¹⁶ With regard to uncertainty about the legal and practical aspects, refer also to Ganzini et al. 2001.

partly because they were concerned about being subjected to sanctions by their employer.²¹⁷

A further two studies broach the subject of physicians' experience of self-administered assisted dying. Evidence of the emotional strain of participating in self-administered assisted dying arise in the aforementioned case-control study in Oregon from 1999 (see Subsection 4.3.4).²¹⁸ The questionnaire survey from 1999 of just over 2,600 physicians in Oregon revealed that, of the 29 physicians who said they had prescribed medication for self-administered assisted dying, four were ambivalent about their participation and one of them had decided not to participate again.²¹⁹

Other countries

As early as the beginning of the 1980s, the Dutch Medical Association endorsed the legalisation of euthanasia and played a central role in the development of the so-called due care criteria, which were incorporated into the law in 2002 (see Subsection 3.2.1).²²⁰ Assisted dying is currently widely supported within the medical communities in the Netherlands and Belgium. In a Dutch study from 2011–2012, more than four out of five of the 1,456 physicians who responded said that they would consider granting a request for euthanasia if it related to cancer or another physical illness (if it related to dementia, tiredness of living or a psychiatric illness, around a third said they would consider participating).²²¹ In a 2009 study from Belgium, 90 per cent of the 914 physicians who responded felt that assisted dying was acceptable for terminally ill patients who are suffering unbearably. Furthermore, 60 per cent thought it might be acceptable to perform a procedure that aims to shorten the life of patients who are not capable and find themselves in the same situation.²²² There is also widespread support among nurses in Belgium. In a study from Flanders, 96 per cent of 3,733 nurses who responded supported assisted dying for the terminally

²¹⁷ Also refer to Ganzini et al. 2001.

²¹⁸ Chin et al. 1999.

²¹⁹ Ganzini et al. 2000.

²²⁰ Rietjens et al. 2009.

²²¹ Bolt et al. 2015. Also refer to Kouwenhoven et al. 2013.

²²² Smets et al. 2011 (the response rate was 34 per cent in this study).

ill. The vast majority also believed that nurses should be involved when the decision about assisted dying is made.²²³

In the Netherlands, too, physicians testify to mixed feelings in connection with performing the act of assisted dying. In a study from 2001 of Dutch physicians who had participated in assisted dying, 75 per cent said that they experienced feelings of discomfort (burden, emotional tension or heavy responsibility) after having performed euthanasia.²²⁴ At the same time, 52 per cent felt satisfaction or relief. For self-administered assisted dying, the figures were 58 and 63 per cent respectively. The study does not indicate any signs of a “numbing” effect. It was just as common for the physicians to feel that the latest case of euthanasia was harder than the one before that, as the opposite. Despite the emotional strain, as many as 95 per cent of the physicians were prepared to perform euthanasia again.

The Canadian Medical Association has welcomed the 2016 law on assisted dying and support physicians’ rights to follow their own conscience, regardless of whether this applies to participation in or opposition to assisted dying.²²⁵ An attitude survey carried out in 2014 of almost 5,000 Canadian physicians showed that 45 per cent were in favour of legalisation and 42 per cent were against. 27 per cent said that they probably would participate in assisted dying if it was legalised.²²⁶ Canada is the only country where even certain nurses can perform assisted dying and, although the vast majority of cases of euthanasia (there is hardly any self-administered assisted dying in Canada) are performed by physicians, the number of cases in which nurses are performing euthanasia is rising. During the first six months of 2017, nurses accounted for 4.3 per cent of all cases of euthanasia.²²⁷

The Swiss Medical Association believes, just as does the Swiss Academy for Medical Sciences (see Subsection 3.3.1), that participation in self-administered assisting dying is not part of a physician’s tasks, but that it should be respected as an act of con-

²²³ Inghelbrecht et al. 2009.

²²⁴ Haverkate et al. 2001.

²²⁵ Canadian Medical Association 2017.

²²⁶ Canadian Medical Association (n.d.)

²²⁷ Health Canada 2017

science.²²⁸ In a survey from 2014 of almost 5,000 Swiss Medical Association members, 73 per cent felt that self-administered assisted dying should be permitted, whereas 43 per cent would potentially consider participation.²²⁹

4.8.4 Population

Oregon and Washington

Data indicates that support for the Death with Dignity Act among the people of Oregon has grown. The second time the law was proposed in a referendum (1997), it was supported by 60 per cent of the voters. In 2012, according to a study, support was at about 80 per cent among potential voters.²³⁰ There was a majority in favour of the law across all income brackets and educational levels, as well as all ethnic groups. The only group with a majority (58 per cent) opposed to the law was the group that attended church at least once a week.

No data has been found concerning attitudes to the law among vulnerable groups. In a small focus group study in Oregon involving twelve people with various disabilities, some supported the law, others were against it, and some did not have a clear opinion. Several of those opposed to the law expressed a concern that negative attitudes to people with disabilities on the part of the healthcare system, as well as a weaker position in society, financially and socially, would lead to the decision about requesting self-administered assisted dying not being entirely voluntary for some people with disabilities.²³¹

Other countries

As part of the European Value Study, a longitudinal survey of European citizens' values, the citizens of 23 European countries were

²²⁸ Fédération des médecins suisses 2008.

²²⁹ Brauer, Bolliger and Strub 2015. The sample in the study was weighted towards particularly relevant specialities, such as oncology, neurology and geriatrics. 1,318 physicians completed the questionnaire (27 per cent response rate).

²³⁰ Sandeen 2013.

²³¹ Drum et al. 2010.

asked to rate their support for euthanasia. In the Netherlands, support for euthanasia has grown since the first survey in 1981. On a scale of one to ten, support for euthanasia in the past two surveys, carried out in 1999 and 2008 respectively, was at an average of 6.7. In Belgium, the average support in 1981 was 3.5. In 2008, the first time the survey was carried out after legalisation in 2002, support had increased to 6.8.²³²

In 2011, in the Swiss canton of Zürich, the inhabitants voted down a proposal to ban self-administered assisted dying with 84 per cent of the votes. A proposal to limit self-administered assisted dying to the inhabitants of the canton and thereby stop “suicide tourism” from other countries was voted down with 78 per cent of the votes.²³³

In a 2016 survey by public opinion institute Ipsos in Canada, 85 per cent of the respondents supported the Supreme Court’s decision from the previous year to lift the ban on assisted dying.²³⁴

²³² Cohen et al. 2013.

²³³ Neue Zürcher Zeitung 2011.

²³⁴ Ipsos 2016.

5 Arguments for and against assisted dying

Arguments for and against assisted dying can be schematically divided into value-based arguments and fact-based arguments. Value-based arguments address the principles or values that should, it is thought, carry more weight when considering whether assisted dying should be permitted. Fact-based arguments address the alleged factual circumstances believed to be relevant to the position.

The self-determination argument is a prominent value-based argument in favour of the legalisation of assisted dying, whereas the argument about the sanctity of life is a frequent value-based argument against. Common fact-based arguments in favour of assisted dying are that it would contribute to reduced suffering and counteract a low quality of life and loss of dignity at the end of life. Common fact-based arguments against assisted dying are that it would reduce confidence in healthcare, lead to palliative care being overlooked and lead to a slippery slope, where assisted dying is prescribed to an increasing number of patient groups.

5.1 Value-based arguments and fact-based arguments

When describing the ethical discussion about assisted dying, it is important to differentiate between arguments that refer to values or ethical principles (value-based arguments) and arguments that refer to alleged facts (fact-based arguments). Value-based arguments address the principles or values that should, it is thought,

carry more weight when considering whether assisted dying should be permitted. A classic value-based argument in the debate on assisted dying is that assisted dying violates the principle of the sanctity of life which, according to some debaters, is considered to be superior to any other possible values that could be promoted through assisted dying.

Fact-based arguments are not about which values should guide the position on assisted dying, but the alleged factual circumstances believed to be relevant to the position. One example is the claim that there are situations where conventional pain management is not sufficient to ease the suffering (and where assisted dying would offer a solution). To start with, it should be noted that fact-based arguments are also *based on values* (in order to be relevant, the suffering argument assumes that reduced suffering is a thing of value).²³⁵ Furthermore, not all fact-based arguments are based on facts, in other words, substantiated by fact. On the contrary, the debate about assisted dying contains many claims about the consequences of introducing a law without providing any substantiating evidence. The difference between fact-based arguments and value-based arguments is that the former can be substantiated by observations of real life (is there any suffering that cannot be alleviated with conventional pain management?). Many believe it is impossible to substantiate value-based arguments through observations in the same way.

Based on this distinction between value-based and fact-based arguments, some common arguments in the debate on assisted dying are outlined below, as well as some of the counterarguments. However, it should be noted that not all arguments can easily be placed in one of the two categories. In the actual debate, there are also a lot of arguments that are a combination of value-based and fact-based arguments. This type of argument might, for example, say that, assuming there is a certain fact about assisted dying, then a certain value should be prioritised.

It could be argued that the list does not differentiate between arguments for or against the claim that assisted dying may be ethi-

²³⁵ The underlying values are often revealed in the wording of the arguments, as when people say that assisted dying implies a “risk” or a “chance” of a certain effect. These types of misleading terms have been avoided as far as possible in the description of the various fact-based arguments in this chapter.

cally justifiable and arguments for or against the legalisation of assisted dying. You can, for example, be of the opinion that assisted dying does not necessarily always have to be morally wrong, yet still feel that there are ethical and judicial arguments against legalisation. You can also hold a personal opinion that assisted dying is unethical, but nevertheless feel that the government should not deny capable adults the choice. What the debate is ultimately about, however, according to Smer's assessment, is the matter of legalisation. Those arguing that it may be ethically justifiable to help another person end their life usually do this to support a call for the legalisation of assisted dying. Those arguing the opposite case, that assisted dying is not ethically justifiable, usually wish by doing this to support the position that assisted dying should not be permitted.

5.2 Value-based arguments in favour of permitting assisted dying

5.2.1 The self-determination argument

One value-based argument that is often put forward by advocates of assisted dying relates to the right to self-determination. The strongest version of the argument presupposes that people have a right to make decisions about themselves and their lives, which also includes a right to decide how they wish to end it. Those not arguing for self-determination in terms of absolute rights can instead argue that society should assume that the individuals know what is best for them and respect their choices as far as possible. It is often pointed out that there is an increased focus on respect for self-determination in healthcare today, and it is believed that in the final stages of life, self-determination can be particularly important.

A counterargument that is sometimes directed at this argument is that self-determination does not extend as far as the right to assisted dying, as it would infringe the self-determination of the person expected to perform assisted dying (but advocates usually disagree that the right to self-determination would mean another individual, physician or otherwise, is obliged to provide assisted dying). Another value-based counterargument is that this view of self-determination does not take into consideration the fact that people

are part of social contexts, where those around them - in this case, for example, healthcare professionals and relatives - also have interests that must be considered.

One argument related to the self-determination argument is that it is undemocratic to deny others assisted dying because you personally think it is wrong. It goes against the fundamental principle that a majority may not impose its values on a minority with regard to decisions that only apply to the actual individual.

5.2.2 The democracy argument

Advocates for assisted dying sometimes point to the fact that a clear majority of the population believes that patients at the end of life should have access to assisted dying. Implicitly there appears to be an assumption that a ban would, therefore, be undemocratic.

5.2.3 The justice argument

Today there is a broad consensus that a capable patient has the right to decline life support. Patients at the end of life who are receiving some form of life support can thereby in effect decide to end their life if they, for example, feel that their quality of life is too low. According to some advocates for assisted dying, from the principle of “treating like cases alike” it follows that patients at the end of life who are not receiving life support should be allowed to determine their own death in another way.

5.2.4 We should regulate a practice that already exists

An argument for the legalisation of assisted dying that is in the grey area between fact-based and value-based arguments is that it would create a regulatory framework for something that allegedly already exists. This is factual in the sense that it contains a factual claim, that assisted dying would occur in the healthcare system (which is not undisputed). At the same time, it is value-based in the sense that it seems to assume that assisted dying is a good thing, or at least something that ought not be penalised.

5.2.5 The dignity argument

One argument in favour of assisted dying is that it would give severely ill patients a chance to end their life in a dignified manner. If this is based on the view that certain medical conditions can lead to life ending in a way that in itself is undignified, the argument seems to be value-based. If the emphasis is more on the patient's experience of dignity, it can rather be seen as a variation of the suffering argument (see Subsection 5.3.3), in other words a fact-based argument.

5.3 Value-based arguments against permitting assisted dying

5.3.1 The argument about the sanctity of life

One argument that is sometimes put forward by those who are opposed to assisted dying is that it goes against the principle of the sanctity of life. According to this principle, it is always wrong to intentionally end a human life, whether or not you have the person's consent. A parallel is sometimes drawn with slavery: you may not voluntarily make yourself someone else's slave, as it is wrong to turn people into possessions. The argument about the sanctity of life is often based on religious conviction (as when people are accused of "playing God" for ending another human life), but need not be religion-based.

5.3.2 Assisted dying goes against medical ethics

Another value-based argument against assisted dying is that it is incompatible with the principles of medical ethics. These principles are sometimes summarised in the words "never harm, cure if possible, relieve often and console always." It is also said that a physician's duty is to preserve not take life.²³⁶ Advocates for assisted dying usually counter this claim by arguing that medical ethics

²³⁶ According to the American Medical Association, euthanasia and self-administered assisted dying are "fundamentally incompatible with the physician's role as healer", see American Medical Association (n.d.).

should evolve as the rest of society does. To illustrate, they often refer to the shift from medical paternalism to patient autonomy that has allegedly occurred in recent years. Assisted dying would be just another phase of this development.

5.3.3 Assisted dying means the patient misses out on an important phase of life

It is sometimes argued that, in the right circumstances, the final phase of life can be a time of deeper insight and maturity. Relationships come to the forefront and patients seek to resolve conflicts and reconcile themselves with their loved ones. They look back on their lives and accept death rather than resist it. If the patient chooses assisted dying, they risk missing out on this important phase of life, according to the argument. A closely related argument is that the call for assisted dying reflect a general shift in attitude in the society, where people are finding it increasingly difficult to deal with life's trials and instead seek simple, painless escape routes.

5.3.4 The dignity argument

The dignity argument is also used by those who are opposed to assisted dying. Human dignity is said to be linked to our very existence as humans and is not something that is affected by suffering or a lack of autonomy. This dignity can only be maintained if life is maintained. Which is why assisted dying is incompatible with human dignity.

5.4 Fact-based arguments in favour of permitting assisted dying

5.4.1 Assisted dying can be a final way out when symptom management is insufficient

Even if medical development is advancing, according to some advocates there are still situations in which the healthcare falls short and severe symptoms such as pain, anxiety, nausea and dyspnoea can-

not satisfactorily be alleviated. In special cases like these, when other methods do not suffice, assisted dying would be able to offer a last resort in order to reduce extreme suffering.

5.4.2 The compassion argument

Closely linked to the suffering argument is the compassion argument, which is raised, not least, in the Dutch debate. According to the argument, assisted dying should be seen as an opportunity for a physician to show compassion for their patient when all other options for alleviating the patient's torment have been exhausted.

5.4.3 Assisted dying can counteract low quality of life and loss of dignity in the end of life

When patients who wish for assisted dying are asked about the reasons for this, their answers are not just about physical suffering, but often about suffering of a more social or existential nature, such as quality of life, a reduced ability to partake in activities that make life enjoyable, loss of independence, loss of dignity, loss of control over their bodily functions and a feeling of being a burden on their relatives (see Subsection 4.3.3). Advocates of assisted dying maintain that medical progress, which means an increasing capacity for keeping people alive, can lead to prolonged dying and a deteriorating quality of life at the end of life. The increased self-determination that assisted dying would entail, would in their view be a means for preventing this.

5.4.4 Assisted dying gives patients security and control at the end of life

A closely related argument is that assisted dying would create a greater sense of security for patients who are told they have an incurable disease (such as cancer or certain neurodegenerative diseases) that will develop with increasingly severe symptoms until death occurs. Knowing that assisted dying is there as a final resort if the symptoms become too severe or if dignity is lost would, ac-

ording to some advocates for assisted dying, provide a feeling of control that makes it easier to make the most of the time they have left.

5.4.5 Assisted dying can lead to fewer suicides

One variation on the sense of security argument is that assisted dying would lead to fewer suicides. Data shows that the elderly are overrepresented in the suicide statistics, and that people who have just been diagnosed with cancer are highly overrepresented.²³⁷ It is sometimes argued by advocates for assisted dying that these suicides might be fewer if people knew that they had the option of assisted dying.

5.5 Fact-based arguments against permitting assisted dying

5.5.1 Where there is good access to palliative care, there is no need for assisted dying

One counterargument to assisted dying is that palliative medicine is currently said to have satisfactory methods for addressing pain, anxiety and other symptoms that are common at the end of life. Even loss of dignity and existential suffering can be avoided with expert and compassionate palliative care. By knowing that they have access to this type of care, the patient can feel secure about dying without assisted dying having to be an option.

5.5.2 The question of assisted dying is discussed by healthy people, whereas those who are ill do not request it

According to this argument, most of the people calling for the legalisation of assisted dying are healthy people who imagine that a life with a severe illness would not be worth living and that they would rather choose to die than live with the dependency and func-

²³⁷ Fang et al. 2012.

tional limitations that is often characteristic of the final days. It is argued that people generally have limited knowledge of the symptom relief options that are available, and therefore imagine dying to be more agonizing than it actually is for most patients (see previous argument). Moreover, people's values change when they are close to death and they value different things to when they were healthy. Which is why, it is argued, there is (almost) no demand for assisted dying among those who are actually concerned by it.

5.5.3 The care of other patients may deteriorate

Another argument that is often directed against assisted dying is that it might have a negative impact on the care of other patients. It is predicted that it would be more common for patients' lives to be terminated without their consent (see below regarding the 'slippery slope') or that decisions not to initiate or continue life support would be affected due to a change in the staff's opinion of when a life is worth living. That palliative care would risk being neglected and that assisted dying could become a way to resolve resource shortages are other arguments. Another consequence sometimes discussed is that suicide prevention work would suffer, as it would be hard for the healthcare system to be both "in favour of" and "opposed to" suicide.

5.5.4 Confidence in the healthcare system may decline

Simply knowing that assisted dying exists within the healthcare system would, according to some opponents, have a detrimental effect on the general public's confidence in the healthcare system. In order to preserve public confidence in the healthcare system, it has been suggested that, if assisted dying is introduced, a different occupational group than healthcare staff should perform it.

5.5.5 Medical assessments are uncertain

Those who are opposed to assisted dying sometimes suggest that the diagnoses and prognoses upon which decisions about who is

eligible for assisted dying are based are unreliable. Even assessing life expectancy, as required by the Oregon Model is difficult. Assessing whether someone's suffering is unbearable, as in the Benelux Model, is even harder. In all probability, the assessment will be coloured by the assessor's own values.

5.5.6 Patients who request assisted dying are often depressed

Those who are opposed to assisted dying sometimes argue that everyone has an intrinsic will to live, and that a desire to die, even in the terminally ill, is a sign of depression. This theory is sometimes linked to the (value-based) argument that it would be wrong to treat depressed patients at the end of life any differently from other depressed patients. As depression, even at the end of life, can be treatable, they should, therefore, be offered treatment for their depression, not assistance with dying.

5.5.7 It is difficult to guarantee that the patient is capable

It is also pointed out by opponents that a depressive disorder can affect the ability to make an informed decision (decision-making capacity). It is difficult, some say, to rule out patients whose wish to die is more likely to be evidence of depression than of a carefully considered decision. It is also difficult to determine how possible cognitive impairment or psychiatric disorders affect the ability to make informed decisions. Assessing decision-making capacity will, according to some opponents, probably be affected by the physician's attitude to assisted dying.

5.5.8 It is difficult to establish whether the request for assisted dying is voluntary and enduring

According to this argument, it is difficult to limit assisted dying to those patients who request it of their own free will and harbour an enduring and carefully considered desire to end their life. It is said to be difficult to rule out external pressure or expectations, or that

patients choose assisted dying to avoid being a burden on others. Furthermore, it is stressed that the will to hasten death in patients at the end of life often wavers from day to day and, in a lot of cases, is related to underlying problems such as poor symptom management, despair or loneliness. Once these problems are dealt with, it is argued, the desire to hasten death often goes away. It is also stressed that a will to die can sometimes be the manifestation of a traumatic reaction after an accident or diagnosis.

5.5.9 The view of humanity in society could change if assisted dying is permitted

Some of those who are opposed to assisted dying predict that legalisation would lead to changed values in society. The principle of human dignity (i.e. the notion that everyone is of equal value regardless of personal characteristics and social standing) could be under threat, and a view that some lives are not worth living could develop. It is also sometimes argued that assisted dying is in direct *conflict* with the principle of human dignity. This is, however, more of a value-based argument than a fact-based argument (see subsection 5.3.4).

5.5.10 The slippery slope

A common fact-based argument against assisted dying is that it would lead to a “slippery slope”. Usually this refers to a process where the criteria for access to assisted dying are broadened in a way that was not intended at the time of its introduction, for example, from terminal illness to tiredness with life, from physical illness to mental illness, or from voluntary assisted dying to non-voluntary. One idea put forward is that, when assisted dying is available, more and more patients will request it, which will lead to physicians having difficulty in maintaining the current restrictions. Practice thereby gradually shifts towards an increasingly permissive attitude to assisted dying.

Sometimes the term ‘slippery slope’ is also used of a process where a broadening of the criteria occurs quite openly, through legislation, precedent or authority decisions. The argument in this

case is that it is not possible to limit assisted dying to a certain patient group, because once “the genie has been let out of the bottle,” the pressure to grant more and more groups access to assisted dying will be impossible to resist.

5.5.11 “Doctor shopping”

One phenomenon that those who are opposed to assisted dying sometimes warn about is so-called “doctor shopping”. This means that patients who are denied assisted dying by their regular physician keep searching until they find a physician willing to provide assisted dying. According to some opponents, this could lead to a broadening of the criteria for assisted dying.

5.5.12 Specific risks to vulnerable groups

With regard to various possible negative consequences of assisted dying, many opponents argue that certain groups, such as financially weak groups, the elderly, the chronically ill, the mentally ill or people with disabilities, would be particularly vulnerable. It is among these groups in particular that it is believed that confidence in the healthcare system could be damaged by the knowledge that assisted dying exists. The likelihood of choosing assisted dying for financial reasons, due to perceived external pressure or not wanting to be a burden, could be particularly high if you belong to a vulnerable group. Similarly, a potential ‘slippery slope’ could affect these groups in particular. If the principle of human dignity is not maintained, it could lead to a decrease in society’s will to invest resources in the maintenance of a good quality of life for people who are sick or disabled.

5.5.13 Assisted dying can fail

One argument against assisted dying is that the methods used for assisted dying are said to be not entirely safe. It is argued that the medications used do not always achieve the desired effect and the patient does not die or dies a painful death.

5.5.14 Assisted dying is a burden on healthcare staff

Those who are opposed to assisted dying sometimes raise the argument that this kind of practice would have a negative impact on physicians and other healthcare staff. Ending a person's life is, they believe, always an emotionally stressful act, regardless of whether there is consent. Assisted dying could also lead to stigmatisation of physicians as a professional group.

6 Analysis and conclusions

This chapter analyses the evidence that supports the fact-based arguments for and against assisted dying presented in the previous chapter, based on data obtained during the knowledge review in Chapter 4. The analysis focuses on the Oregon Model. Some of the conclusions are that:

- Data strongly supports that the motives for requesting assisted dying are multifactorial, where dignity, independence and quality of life often outweigh pain and other symptom-related factors. There is also evidence that a disinclination to be a burden on those around them is often a motivating factor.
- Data provides some support for the claim that assisted dying contributes to a sense of security and a feeling of control for the patients.
- Data provides some support for the claim that access to good palliative care can reduce the demand for assisted dying. At the same time, the patients' motives for requesting assisted dying contradict the notion that palliative care can eliminate demand entirely.
- Data contradicts the notion that expansion of palliative care would suffer should assisted dying be permitted.
- Data strongly contradicts the notion that socioeconomically disadvantaged groups are overrepresented.
- Data contradicts that a large proportion of patients who request assisted dying are depressed but provides some support for the notion that people with depression are overrepresented.

- The regulations in Oregon have remained the same over the years, which contradicts the notion that a gradual broadening of the criteria is inevitable. However, there is no data relating to a ‘slippery slope’ outside the regulations, for example, assisted dying for non-terminal patients.
- There is no reliable data relating to the impact assisted dying has on the suicide rates.
- There is no data that shows the extent to which the criteria on decision-making capacity has been maintained.
- There is no data that illustrates the impact on confidence in the healthcare system and possible changes with regard to attitudes to people.

6.1 Introduction

This chapter aims to assess the supporting evidence for some of the most common fact-based arguments in the Swedish debate on assisted dying, based on the data – in the form of research findings and statistical data relating to the application of assisted dying – presented in Chapter 4.

An important point that arose during the review of research and public statistics from countries that permit assisted dying is that the question of to what the consequences of introducing assisted dying would be can only be answered if the model being referred to is specified. For example, assisted dying is ten times more common in Belgium and the Netherlands – which permit euthanasia, allow advance healthcare directives and have no criteria for terminal illness – than in Oregon and Washington, which only permit self-administered assisted dying, do not accept advance healthcare directives and have terminal illness criteria. In Switzerland, where the only legal requirements are that the patient is capable and the person assisting the death does not stand to gain anything from the death, the proportion of women, the elderly and patients without terminal illness is higher than in other countries where assisted dying is legal.

As the model that has mainly been presented in the Swedish debate in recent years is the Oregon Model, the emphasis in the re-

view of statistics and research has been on that model. For the same reason, the arguments have primarily been analysed in relation to the Oregon model and what is known about it, whereas data relating to other models is mainly presented to put into perspective what is revealed about the Oregon Model.

The fact-based arguments are presented in the same order as they are presented in Chapter 5 (Subsections 5.4.1 to 5.5.14). For a description of the arguments, please refer to that chapter. For references and more detailed descriptions of studies and other source texts mentioned below, please refer to Chapter 4.

As noted in Chapter 5, there are also values behind fact-based arguments which, for example, can be revealed in the way the arguments are worded. For this reason, the arguments have been put as questions throughout, where emotional or loaded words have been avoided.

When a fact-based argument has been examined, the first question has been whether it has been at all possible to find any information in the data reviewed that is relevant to the factual claim that the argument is based on. As illustrated below, the answer in many cases is no.

Cases like these, where there is no data that allows us to consider an argument, must be isolated from cases where there is data to support their counterarguments. The fact that we cannot determine whether an argument is correct due to lack of knowledge should not be interpreted to mean that it is wrong. Therefore, below we have avoided the somewhat ambiguous wording “lacking evidence” for an argument. When the available data is thought to rebut the argument, instead the wording used is that the data “contradicts” it.

The fact that data supports or contradicts an argument means, in the following information, that the studies and statistical material that have been reviewed point either in one or in another direction. This does not mean that the argument is “proved” or “disproved”. In some cases, however, the data available speaks strongly and unanimously for or against the argument. In these cases, this is emphasized in the text. Finally, it should be noted that there may sometimes be data that puts a matter into perspective without actually speaking for or against the argument. This type of information is also presented in the review.

6.2 Fact-based arguments for assisted dying

6.2.1 Could assisted dying be a last resort when symptom management is insufficient?

The literature reviewed in this report does not cover the issue of whether there are situations where even the best palliative care is unable to satisfactorily manage symptoms such as pain, anxiety, nausea and dyspnoea, or whether the methods available in modern palliative care in the vast majority of cases provide sufficient symptom management.

However, what research and statistics from countries and states that have legalised assisted dying provide strong and unanimous support for is that the reason for requesting assisted dying is often multifactorial where, a lot of the time, pain and other physical symptoms are not the only or even the most important reason. In fact, a couple of studies indicate that the patients who die through self-administered assisted dying in Oregon have fewer illness-related symptoms than other patients who die from the same illnesses.²³⁸

As shown in Chapter 4, suffering is a more common motive for assisted dying in the Benelux countries than in Oregon and Washington. That suffering is a more common reason in the Benelux countries, in particular when you ask the physicians, probably reflects the fact that unbearable suffering is included in the criteria for assisted dying in these countries. At the same time, the Oregon Model seem to be less suitable than the Benelux Model to serve as a (last) resort for treating intractable symptoms, at least in cases where there is a rapid escalation of symptoms towards the end of the patient's life. Data from Oregon indicates a stronger correlation between experiencing severe symptoms, particularly during the final week of life, and *considering* self-administered assisted dying than *dying* through self-administered assisted dying. This has prompted the comment that the strict criteria on a waiting period (at least 15 days between the first request and prescription of the medication) and on decision-making capacity (no advance

²³⁸ According to a study from Washington, however, for patients who use the medication when death is extremely imminent, illness-related factors are of greater significance in taking the decision.

healthcare directives are approved) could mean that patients who request assisted dying due to severe symptoms may not have enough time to complete all of the necessary steps, alternatively that they are so cognitively impaired that they fail to live up to the decision-making capacity criterion. In addition, the patient must be capable of ingesting the medication themselves. The fact that the Benelux Model lacks fixed time limits, accepts advance healthcare directives²³⁹ and permits euthanasia may, in this regard, make a significant difference.

The experiences from Canada can also be mentioned here, where euthanasia is permitted but where you cannot provide advance healthcare directives. At the University Hospital Network in Toronto, where a framework to provide access to assisted dying in the hospitals has been implemented, the position now is that it is neither desirable nor feasible to administer euthanasia as an emergency measure in the very end of life. Instead, palliative sedation is seen as an option in unbearable suffering at the very end that cannot be relieved in any other way. Experience has demonstrated that a lot of patients requesting euthanasia just hours or days before their natural death are denied it because they have lost their decision-making capacity, for example, as a result of intense symptom management, while at the same time the process takes time and energy away from the patient and their relatives at the very end of life.²⁴⁰

To summarise the data reviewed provides strong and unanimous evidence to support that severe symptoms are a less important reason for requesting assisted dying on the part of a large proportion of the patients. At the same time, there is information to suggest that the Oregon Model, due to the 15-day waiting period and the lack of advance healthcare directives, may not be as good an emergency option for unbearable symptoms.

²³⁹ The regulations for advance healthcare directives, however, are stricter in Belgium and Luxembourg than in the Netherlands.

²⁴⁰ Li et al. 2017.

6.2.2 Could assisted dying counteract low quality of life and loss of dignity at the end of life?

Unanimous data from the healthcare authorities and from other studies shows that low quality of life, loss of dignity and independence, and loss of control over bodily functions are important reasons for patients in Oregon and Washington to request assisted dying. What characterises patients who request assisted dying, at least in Oregon where this has been investigated, seems to be that, for them, these aspects in particular are more important for a good death than for other patients. Certainly, the fact that someone wishes to achieve a certain effect by requesting assisted dying does not necessarily mean that they will actually achieve this effect. With that reservation, the data reviewed nevertheless provides relatively good supporting evidence to argue that the Oregon Model contributes to positive final hours in this regard.

6.2.3 Can assisted dying give patients security and control at the end of life?

Studies show that for many of the patients in Oregon who request assisted dying, the reason is not the loss of control, dignity or pain experienced at that particular time. Instead, a lot of the time it is more about wanting to anticipate future problems. There is data from Washington that some patients save the medication for future use and that they state that the medication gives them a feeling of control in an uncertain situation. Altogether, this provides some evidence to support that the security aspect may be an important motive for many people in Oregon and Washington who request self-administered assisted dying. The fact that as many as a third do not use the medication is an observation that is consistent with this. One possible explanation why patients do not use the medication could, however, also be that they change their minds and no longer wish to hasten death. Here, more research would be required into the reasons why so many of the patients do not use the medication.

6.2.4 Can assisted dying lead to fewer suicides?

Estimating what effect the legalisation of assisted dying would have had on suicide rates is difficult because of the large number of variables that affect them. The attempt that has been made to estimate this effect has shown an increase in the total number of suicides (including cases of self-administered assisted dying) in Montana, Oregon and Washington. Among people aged 65 and above, a reduction (not statistically confirmed) in the number of suicides was observed when cases of self-administered assisted dying were not included. However, these results are to be viewed with caution due to the difficulties in determining how the development would have progressed if assisted dying had not been introduced. The conclusion is that there is no reliable data when it comes to self-administered assisted dying having a possible impact on the suicide rates.

6.3 Fact-based arguments against assisted dying

6.3.1 Is there no need for assisted dying where there is good access to palliative care?

Data from the years following the legalisation in Oregon shows that up to half of the patients who requested assisted dying and subsequently received a substantial medical intervention, such as referral to a hospice program, changed their minds and no longer wanted assisted dying. A study of cancer patients carried out in 1998–2001 found a statistically significant correlation between experiencing a low quality of care and an interest in self-administered assisted dying. This data provides some support for the claim that access to quality palliative care can reduce the demand for assisted dying.²⁴¹

Both of these studies are, however, relatively old and since they were carried out the proportion of patients in Oregon and Washington with access to palliative care at the time of their death has

²⁴¹ It appears that access to types of care other than palliative care could also have such an effect. Some physicians in Oregon with patients who had requested self-administered assisted dying reported that a promise to be available throughout the course of the illness made the patients more willing to consider alternatives.

increased. This applies both to all deceased patients and to those who die through self-administered assisted dying. Nevertheless, the proportion of patients opting for assisted dying is increasing. This suggests that it is not just a lack of access to palliative care that is causing patients to request self-administered assisted dying, at least not in Oregon and Washington where there is good access to palliative care. It should be noted that neither in the Benelux countries has the increase in the number of euthanasia cases slowed as palliative care has expanded.

One explanation for the increasing demand for assisted dying despite more patients being offered palliative care could be that the care being offered is in certain cases unable to provide adequate symptom management (perhaps in combination with increased expectations of the healthcare system when it comes to managing physical and other symptoms). Whether palliative care is always able satisfactorily to manage symptoms such as pain, anxiety, nausea and dyspnoea, or whether even the best palliative care sometimes falls short (which is argued by some advocates for assisted dying) is not an issue that is covered by the literature reviewed in this report. Nor have any studies been found that compare the quality of palliative care in Oregon and Washington with other states and countries. Which is why there is no supporting data for assessing whether the requests for assisted dying in Oregon and Washington due to unsatisfactory symptom management could be expected to be fewer with *access to better* palliative care, unlike *better access to* palliative care, which has not decreased the demand for assisted dying.

Inadequate symptom management, however, is only one – and less important – reason for requesting assisted dying. Research that has been carried out about the motives in patients who choose self-administered assisted dying shows that, for many of them, the experience of a dignified death is linked to things such as control over death and maintaining independence, needs that cannot necessarily be met through palliative care. On the contrary, some patients seem to choose assisted dying specifically to avoid dependence on care.

To summarise, there is data that to some extent supports the idea that access to good palliative care can lead to assisted dying being requested to a lesser degree. At the same time, there is data

to suggest that palliative care, regardless of quality, cannot meet the needs of all patients who request assisted dying.

6.3.2 Is there no demand for assisted dying among people who are severely ill?

According to one argument, legalisation of assisted dying is an issue that is primarily initiated by healthy people, while there is virtually no demand among those who are actually concerned by it, severely ill patients. Among motor neurone disease and cancer patients in Oregon, a few per cent at most wish to end their own lives through self-administered assisted dying. This suggests that most patients suffering from a terminal illness value the time they have left and have no wish to hasten death. If you compare the small number of patients who actually choose self-administered assisted dying with the strong support for the Death with Dignity Act among the people of Oregon (which according to a survey is as many as 80 per cent), you can in a sense argue that it is primarily among healthy people that there is an interest in assisted dying.

At the same time, in Oregon and Washington there is a growing number of people who have been diagnosed with a terminal illness who are requesting self-administered assisted dying. In the Benelux countries, where there are even more patients who die through assisted dying, approximately three quarters are suffering from cancer. That there is no demand for assisted dying among the severely ill is, therefore, a claim that the data strongly contradicts.

6.3.3 Will assisted dying lead to a deterioration of care for other patients?

Will palliative care be neglected if assisted dying is permitted?

In Oregon and Washington, the proportion of patients with access to palliative care at the time of their death is increasing at the same rate as in other US states where self-administered assisted dying is not practised. In Belgium and Luxembourg, laws were passed about the right to palliative care for the terminally ill at the same time as the legalisation of assisted dying, and, since legalisation, these

countries have extended palliative care in terms of structural resources (Luxembourg) and financial resources (Belgium). Also in the Netherlands, since legalisation there has been a substantial growth in palliative care in terms of structural resources. All three Benelux countries are, in this respect, among the seven countries in Europe that invest the most into palliative care. Hence, information from Oregon and Washington, as well as the Benelux countries contradicts the assumption that the development of palliative care would stop if assisted dying were legalised.

It should be clarified that this conclusion applies to the time period that has been studied, i.e. up to a couple of decades after legislation, and does not rule out that the negative effects could occur in the longer term. Therefore, it is important to continue monitoring the development of palliative care both in countries that permit assisted dying and in those that do not. It should also be noted that the data applies to the quantitative development. No data has been found regarding the quality of care provided or whether it differs between counties that permit and do not permit assisted dying respectively.

Are there any other negative impacts on the healthcare system?

With regard to other suggested negative impacts from assisted dying on the care of other patients, no data that illustrates these has been found, either from Oregon/Washington or from any other country that permits assisted dying. This applies, for example, to whether the perception of when continued life support is deemed beneficial to the patient have been affected in a more restrictive direction, so that healthcare staff refrain from treatment more often or whether it happens that assisted dying is used to resolve resource shortages. Nor has any data been found on how the preventive work against suicide may have been affected.

6.3.4 Will assisted dying lead to a loss of confidence in the healthcare system?

No data has been found relating to how confidence in the healthcare system among the population has developed since as-

sisted dying was legalised in Oregon and Washington. Support for the legislation among the population in Oregon is, however, strong and appears to have increased since legalisation. Increasing support for assisted dying among the population is also seen in the Benelux countries and Switzerland. It should, however, be stressed that there is no straightforward correlation between support for assisted dying and confidence in the healthcare system. Support for assisted dying could be evidence of a lack of confidence that patients will receive the care they need in the final stages of life, just as it could be evidence of confidence that they will not be administered assisted dying against their will.

No data has been found relating to the attitude to self-administered assisted dying among specific groups, for example, people with disabilities. Nor has any data been found about how confidence in the healthcare system within these groups has been affected in countries where assisted dying is permitted.

6.3.5 Are the medical assessments uncertain?

Practically every year, the healthcare authorities in Oregon and Washington report about patients who have died through self-administered assisted dying more than six months after they submitted their first request (one patient in Oregon lived for almost three years). There is data from Oregon that between 3 and 10 per cent of the patients live for more than six months after they receive their prescription. In Washington, 15 per cent of the patients who die through self-administered assisted dying are still alive 25 weeks after they submit their first request.

The fact that some patients who receive self-administered assisted dying live for more than six months has been attributed to the particular difficulty of determining with certainty how long a terminally ill patient has left (rather than a deliberate disregard for the regulations). Even if estimates of remaining life expectancy in the vast majority of cases appears to hit the mark, there is evidence to support the claim that there is a degree of uncertainty in the estimates and that they occasionally deviate quite significantly from the actual outcome.

6.3.6 Do patients opt for assisted dying due to depression?

It is not a straightforward exercise to draw a line between what constitutes a natural low spirit when faced with the inevitability of death and what constitutes a treatable depressive disorder in terminally ill patients. Studies that have attempted to differentiate patients suffering from clinical depression have, nevertheless, established that depression is common among patients at the end of life (a systematic survey found a median value of 15 and 29 per cent respectively depending on the diagnostic method). Several studies have also shown that there is a correlation between depression and an interest in hastening death in patients at the end of life. Findings like these have fuelled the argument that behind a wish for assisted dying there often lies a depression.²⁴²

Studies from Oregon show that there are cases of depressed patients requesting and receiving assisted dying. With regard to the question of whether there is a correlation between depression and the demand for assisted dying, the results from Oregon are not entirely conclusive. Patients and relatives rank depression as a less important reason for requesting assisted dying. In a case-control study in which the researchers themselves evaluated the patients for clinical depression they, however, did find a statistically significant correlation between depression and the demand for self-administered assisted dying.

For comparison reasons, it should also be mentioned that a couple of studies from the Netherlands did not show any significant differences in the occurrence of depression in patients who request assisted dying compared to other patients with the same underlying illness. This contrasts with a third study, which is considered to be the most qualitative and which found that depression was three times as common among patients who requested assisted dying.

It should also be stressed that several studies in Oregon and Washington show that the correlation between a wish for assisted

²⁴² The strength of this argument is, of course, highly dependent on the extent to which one considers that a depressive disorder in the final stages of life prevents a patient from making an informed and rational decision about their care. Furthermore, it might be worth remembering that it seems to be a big leap from showing an interest in assisted dying to actually requesting it, see Section 4.5.1).

dying and hopelessness is stronger than the correlation with depression.

To summarise, there is evidence to support the claim that at least some of the patients who request assisted dying in Oregon are actually depressed. There is also evidence, albeit inconclusive, to support the claim that the patients, both there and in the Netherlands, are more frequently depressed than other patients. At the same time, consistent research results from both Oregon and the Netherlands show that a large proportion of the patients who request assisted dying are not depressed. Available data therefore contradicts the idea that a demand for assisted dying might be evidence of depression.

6.3.7 Is it possible to guarantee that the patient is capable?

Depression in itself does not rule out assisted dying, neither according to the Oregon nor the Benelux Model. A patient who is granted self-administered assisted dying in Oregon and Washington must, however, be capable. As depression can affect a person's decision-making capacity and their view of their situation and future possible outcomes (even if it might not always be the case), it is, therefore, important that patients who suffer from depression are identified among those requesting self-administered assisted dying.²⁴³

Based on the limited data available from Oregon, it is not possible to determine whether depressed patients due to an impaired decision-making capacity are denied assisted dying to a greater extent than other patients (the only study found did not show any significant difference in the number of requests granted to depressed and non-depressed patients respectively, but the study data was very limited). From the Netherlands, there are several studies showing that patients with depression are granted assisted dying to a lesser extent than other patients. However, all of the studies, both in Oregon and the Netherlands, show that there are instances where patients, who at some point during the process have been depressed, receive assisted dying. However, it is not always clear if

²⁴³ Levene and Parker 2011.

the patients still suffered from depression when the assisted dying was administered or, if they were, the extent to which it affected the patient's decision-making capacity.

In both Oregon and Washington, a physician who suspects that a patient requesting self-administered assisted dying is suffering from a psychiatric disorder that affects their judgement should refer them to a psychiatrist or psychologist for an assessment. In a handbook produced by the Center for Ethics in Health Care at Oregon Health & Science University, it is stressed that it is difficult for many physicians to diagnose psychiatric disorder or depression and that physicians who are prudent ensure that they refer the patient for psychological evaluation.²⁴⁴ In reality, however, only 4 to 5 per cent of all patients who die through self-administered assisted dying in Oregon and Washington undergo this type of evaluation by psychiatrists or psychologists. One detail also worth highlighting in this context is that, before the law was introduced, many psychiatrists in Oregon doubted their ability, with a single evaluation, to determine the decision-making capacity of a patient suffering from a psychiatric disorder.

A patient's decision-making capacity may be impaired for reasons other than depression or other psychiatric disorder, such as cognitive impairment, which often affects patients at the end of life. Also in these cases, the extent to which these types of patients are identified in Oregon and Washington is unclear.

To summarise, it has not been possible to find any data that illustrates how well, in Oregon and Washington, it is guaranteed that assisted dying is not administered to patients who, as a result of depression or other reason, have a reduced decision-making capacity.

6.3.8 Is it possible to establish whether the request is enduring and voluntary?

Research carried out in Oregon and elsewhere supports the idea that interest in hastening death can vary over the course of a terminal illness. In Oregon, one study found that the interest increased

²⁴⁴ Dunn and Reagan 2008.

with factors such as increasing depression, increasing hopelessness, declining functional status, deteriorating quality of life, decreasing satisfaction with medical care, increasing suffering and an increasing sense of being a burden to the family.

At the same time, few of the patients who show an interest in hastening death go so far as to submit a request for assisted dying. A study in Oregon showed that only one in nine patients who had at some point considered assisted dying submitted a formal request. This suggests that, for the majority of patients, to go from considering assisted dying to actually requesting it is a relatively large step and that, as a rule, if the patient actually goes so far as to submit a request, it is their well-considered and enduring wish. The criterion that the request must be repeated after at least 15 days should also be instrumental in less well-considered requests not being granted. However, it has not been possible to find any studies that have specifically investigated how enduring the wishes were in patients who were granted self-administered assisted dying in Oregon or Washington.

How many of the requests made in Oregon and Washington are voluntary is difficult to say, if nothing else because it is far from clear-cut what is needed for a decision to be considered entirely voluntary. According to the Oregon Model, two physicians must always certify that a patient's request is voluntary, but there do not appear to be any guidelines for determining the limit for whether a request is considered voluntary, or how it should be established. In the aforementioned handbook there is a recommendation that, if there is any doubt about the diagnosis, prognosis and voluntariness, it is preferable to refrain from prescribing medication. There is also a recommendation that a prudent consulting physician (the physician who, according to the regulations, shall confirm prognosis, decision-making capacity and voluntariness, see Subsection 3.1.1) will ensure that the patient undergoes a psychiatric or psychological evaluation in order to establish the decision-making capacity of the patient and the voluntariness of the request. Based on this, it must be stated once again that the proportion of patients who actually undergo this type of evaluation is low.²⁴⁵

²⁴⁵ It should be noted, however, that physicians who have had patients who request assisted dying often describe them as tenacious and resolute people who stand by their decision even

Something that opponents of assisted dying sometimes highlight in connection with the matter of voluntariness is the possibility that the decision to request assisted dying is based on a desire not to be a burden on others. There is a significant amount of data to support that this is a motive for a lot of patients, both in Oregon/Washington and in the Benelux countries. One central question in this context is, of course, to what extent this type of motive means that the decision can be deemed less voluntary. Here it might be worth highlighting the image of the patients found in the research from Oregon. For many of them, autonomy, independence and control seem to be a deeply ingrained part of their identity and sense of dignity. It seems likely that, in many cases, the disinclination to be a burden on others could be about them wanting to safeguard their self-image, rather than evidence of pressure from relatives, who often seem to regard caring for the patient as less burdensome than the patient imagines. Assuredly, this does not rule out the possibility of a more or less explicit pressure from relatives occurring in other cases. Research could contribute to a deeper understanding of the patients' motives on this point.

To summarise, data contradicts the idea that a wish for assisted dying would rarely be enduring, in particular the fact that only a small proportion of patients who at some point consider assisted dying actually make a request. It is unclear what steps have been taken in Oregon and Washington to guarantee that a request is voluntary, bearing in mind the low proportion of patients who are evaluated by psychiatric or psychological experts. However, there is consistent data to support the fact that a desire not to be a burden on those around them is one of several reasons why many patients request assisted dying.

6.3.9 Is the view of humanity in society changing?

No data has been found to illustrate whether, and if so how, people would change their attitude the notion that everyone is of equal

when physicians and relatives are opposed to it. In these circumstances, perhaps an assessment of free will and decision-making capacity may be perceived as less relevant. It may also be difficult to get this kind of patient to accept an assessment of this kind.

value regardless of personal characteristics and social standing in a country or state that has legalised assisted dying.

6.3.10 Are there any signs of a slippery slope?

All reported cases of self-administered assisted dying in Oregon have related to patients who two physicians have confirmed as having a maximum life expectancy of six months. This in itself does not prove that there are no cases in which the patient is not terminally ill. Such cases, if they exist, would be illegal and unlikely to be reported to the authorities. In response to the question of whether there are cases of assisted dying outside the confines of the law, you would need to carry out a systematic follow-up like those performed in the Netherlands and Belgium, where they investigate the circumstances of a large number of randomly selected deaths. The absence of such data means that it is not currently possible to answer the question of whether there is a ‘slippery slope’ in Oregon and Washington in the sense that self-administered assisted dying is administered to patients who have not met the criteria of maximum life expectancy.

The lack of relevant studies means that neither can it be determined whether euthanasia or measures designed to shorten life without explicit consent do occur in Oregon and Washington, and if so, whether it has become more commonplace since the legalisation of self-administered assisted dying. By comparison, studies from Belgium, the Netherlands and Switzerland respectively show that in all three countries there are cases of death being hastened without an explicit request from the patient (in Belgium and the Netherlands the extent is decreasing).²⁴⁶ There are cases of euthanasia in Switzerland despite the fact that it is not permitted.

No data has been found that illustrates whether the interpretation of the decision-making capacity and voluntariness criteria has become more relaxed in Oregon and/or Washington. It is, however, once again noteworthy that the proportion of patients being referred to psychiatrists or psychologists to evaluate whether their

²⁴⁶ According to one of the studies, there are also cases in Sweden and other countries where assisted dying is not permitted.

judgement is impaired due to depression or other psychiatric disorder has decreased considerably in Oregon.²⁴⁷

The criteria for receiving assisted dying has not changed during the 20 years that the Death with Dignity Act has been in force in Oregon. Nor is there any data from the healthcare authorities in Oregon, to which all cases are reported, to suggest any possible changes in the application of the criteria. Developments in Oregon, therefore, contradict the assumption that a slippery slope, in the sense that the regulations are gradually broadened to include more and more patients, would be inevitable if assisted dying were to be permitted. All American states which later legalised self-administered assisted dying have chosen to apply the same criteria as in Oregon.

To summarise, it has not been possible to find data that illustrates whether the legalisation of self-administered assisted dying in Oregon and Washington has led to an increased frequency of assisted dying outside the legal framework. Nevertheless, the actual regulations have been consistent, which contradicts the notion that a gradual broadening of the criteria is inevitable if assisted dying, in any form, were to be permitted.

6.3.11 Does “doctor shopping” exist?

When it comes to so-called doctor shopping, in other words, where patients look for physicians who are more willing to grant assisted dying than others, there is data that indicates this may occur in Oregon. Some patients have only known their physician for about a week when the prescription is issued which, given the requirement for a 15-day waiting period from the first request, means that they made their first oral request to a different physician than the one writing the prescription. It is also noticeable that one single physician accounted for one in eight prescriptions in Oregon in 2016 (25 prescriptions in total). However, there is no information to illustrate that this is related to broadening of the criteria for self-

²⁴⁷ In Belgium, the regulations have changed once since legalisation, when assisted dying was also permitted for children who are terminally ill. In the Netherlands, the regulations have not changed, but there have been discussions about permitting self-administered assisted dying for the elderly who are “finished with life”.

administered assisted dying; it is possible that the first physician said no because they did not want to participate and not because the criteria for diagnosis and decision-making capacity were deemed not to have been met. Here, more research into the motives for the various parties could contribute to greater understanding.

6.3.12 Are vulnerable groups overrepresented?

Data from the health authorities' annual reports and from various research studies consistently contradicts the notion that in Oregon and Washington socially disadvantaged groups might be overrepresented among patients who die through self-administered assisted dying. Compared to patients who died from the same underlying illnesses, patients who choose self-administered assisted dying in Oregon are to a greater extent white, more highly educated and younger (even if a tendency can be seen for them to be getting older). Just as in Washington, they are, to a slightly greater extent, men. The same pattern, with regard to demographics and socioeconomics, can be observed in Belgium and the Netherlands (and, with regard to socioeconomics, also in Switzerland).

With regard to the question of whether patients would choose self-administered assisted dying for financial reasons (a question that is perhaps more relevant in the US than in Sweden, where everyone is covered by the national healthcare system), according to the health authorities' annual reports, this is a subordinate reason. The reports show that virtually all patients have health insurance when they die and that concern about financial implications of continued care is an uncommon reason for requesting assisted dying. The picture painted in the annual reports, which are based on what the physicians report, is backed up by studies from Oregon among patients and relatives, which ranks financial worries as an unimportant reason. This could, of course, be due to the fact that many patients belong to a socioeconomically advantaged group (which the overabundance of highly educated patients indicates), but nevertheless means that there is evidence, at least in Oregon, that financial concern is an unimportant factor behind the decision to request assisted dying.

Explanatory factors put forward for why it is predominantly highly educated patients who die through self-administered assisted dying are that they benefit from the fact that several informative and communicative resources are required to process the bureaucratic elements of self-administered assisted dying. The cost of medication could possibly be a factor that causes some patients in socioeconomically disadvantaged groups to refrain.²⁴⁸ It is also worth considering whether the kind of motives that have proven to be prominent in patients who choose self-administered assisted dying – such as control and independence – might be more prominent in socioeconomically advantaged areas of society.

With regard to people with disabilities and the chronically ill, one should bear in mind that all terminally ill patients suffer to some extent from a chronic illness and most of them also have a disability. No cases were reported to the healthcare authorities in which self-administered assisted dying was granted to people with disabilities or chronically ill patients who were *not* deemed to be terminally ill. With regard to whether or not the patients in Oregon and Washington who received a prescription for self-administered assisted dying had any form of disability or chronic illness before they became terminally ill, no data has been found, which is why it is not possible to tell whether these groups are overrepresented or underrepresented among the patients who die from self-administered assisted dying. Nor does the available data for gender, age, ethnic origin and socioeconomics reveal whether or not there are other “disadvantages” that characterise patients who choose self-administered assisted dying compared to other patients suffering from the same illnesses. For example, it has been suggested that factors such as emotional state, personality type and response to loss could be linked to an interest in self-administered assisted dying.²⁴⁹

To summarise, there is strong evidence to support the claim that potentially vulnerable groups are not overrepresented with regard

²⁴⁸ This explanation assumes that the patients have health insurance. Otherwise, it would no doubt be far more expensive to pay for continuous care than the approximately \$500 that the self-administered assisted dying medication costs.

²⁴⁹ Finlay and George 2011. The recurring descriptions of the patients in Oregon as strong and independent people who are resolute and confident about their choices somewhat contradicts this picture.

to gender, age, ethnic origin and socioeconomics among patients who die through self-administered assisted dying in Oregon and Washington. However, no data has been found that relates to what proportion of the patients had some form of disability or chronic illness before they became terminally ill.

6.3.13 Is it common for assisted dying to fail?

Statistics from Oregon and Washington show that complications associated with self-administered assisted dying are uncommon. The healthcare authorities report that complications such as vomiting or problems ingesting arise in approximately one in twenty cases of self-administered assisted dying in Oregon and Washington. In about one case in 250, the patient woke up again after the procedure. This data contradicts the idea that it would be common for assisted dying to fail.

6.3.14 Is assisted dying a burden on healthcare staff?

There is relatively little data on how physicians and other healthcare staff are affected by being involved in the process of assisted dying. The studies that are available from Oregon and the Netherlands support the claim that many physicians find providing euthanasia or self-administered assisted dying to be a deeply emotional undertaking associated with a strong sense of duty. However, only a few seem to regret the actions afterwards or are not prepared to go through the process again.

From the years following the legalisation in Oregon, there are reports that physicians who were in favour of the law experienced concern that, should they participate in self-administered assisted dying, they would be stigmatised as a result of colleagues or patients distancing themselves. No data relating to whether or not these concerns have materialised has been found.

Data shows that it is very common for nurses and social workers in palliative care in Oregon to discuss self-administered assisted dying with patients. A third of those who had engaged in this type of discussion found it uncomfortable. The nurses and social workers nevertheless felt that, almost without exception, they would not

abandon a patient wishing for access to assisted dying, regardless of their own personal views on the matter.

6.4 Limitations

The review of research and public statistics in this report has focused on data relating to the concrete implementation of assisted dying in countries and states where it is permitted. The assessments in this chapter of what possible evidence there is for the various fact-based argument has been based on this data. It should be stressed that there may be other kinds of factual data relevant for assessing the validity of the arguments, which have not been reviewed.

The conclusions, with regard to what evidence there is for the various arguments, should not be regarded as final. What is provided in the report is an overview of the existing knowledge, a picture that might end up being modified by new research in the future.

Smer also wishes to emphasize that the specification in the report with regard to value-based arguments and fact-based arguments for and against assisted dying does not claim to be exhaustive, although the Council's assessment is that the most common arguments have been covered. There will also be new arguments, and tomorrow's debate may be dominated by different arguments to today's.

The analysis of the existing knowledge in this report has mainly been carried out in relation to the Oregon Model, and the conclusions about the evidence to support the various arguments are also primarily related to that model. Since other factors – such as access to palliative care, the shape of the health insurance system and socioeconomic patterns – may also affect the outcome, for example, with regard to which patients choose assisted dying, it should be pointed out that the conclusions from Oregon cannot easily be transferred to other countries.

6.5 Concluding remarks

The main purpose of this review has been to review the existing knowledge with regard to implementation of assisted dying in the

jurisdictions where this is permitted and, based on this review, to assess the supporting evidence for some of the most common fact-based arguments for or against assisted dying.

The review of what evidence there is to support the arguments, which has focused on the Oregon Model, has shown that two seemingly conflicting opinions – both for and against assisted dying – both contain arguments supported by facts. During the review, we found three types of document for the fact-based arguments raised in the Swedish debate:

- a) Considerable arguments for or against self-administered assisted dying are supported by data from studies or public statistics. These arguments are relevant to the continued debate on assisted dying.
- b) Other arguments conflict with the data available. For the time being, these arguments should be excluded from the debate.
- c) For other remaining arguments, there is no data that speaks for or against the issue – simply put, the matter has not been researched. Such arguments need not necessarily be dismissed, but they should be raised with great caution and the lack of knowledge be emphasised.

Once again, Smer wishes to emphasize that this report has purely attempted to assess the arguments' *sustainability*, in other words, whether or not the arguments' claims about what the consequences of legalising assisted dying will lead to are supported in the existing research and statistics. The arguments' *relevance* for the stance on assisted dying has not been assessed. This also requires an ethical evaluation of how desirable or undesirable the alleged consequences of assisted dying are. As the legalisation of assisted dying, in all probability, may have a variety of different consequences, a final position on assisted dying also requires that various fact-based arguments are weighed against each other, from an individual and a societal perspective. In the final stance, the value-based arguments and their relevance must, of course, also be assessed.

Smer hopes that this review will make it easier for anyone wanting to familiarise themselves with the various different, and sometimes conflicting, factual claims put forward in the debate with regard to the implementation of assisted dying around the world.

At best, the report may help to lay the groundwork for a public debate that relies more heavily on a shared knowledge and, instead of being about what is true and what is false, focuses more on the ethical implications of these facts, and on the compromises and choices that are an integrated part of a position on assisted dying.

In a communication from 2008, Smer urged the government to initiate a commission of inquiry into how patients' self-determination could be increased at the end of life. The proposal gained no support from the government. As this review shows, the past decade has seen a significant increase in the available information that has clarified several of the fact-based arguments raised in the debate. After compiling opinions on this report, Smer will evaluate how the council can further contribute to the public debate on assisted dying.

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Georg Bosshard, Agnes van der Heide and Craig New have contributed information and material for the report.

Prior to the work, a number of organisations were invited to submit their views on relevant questions to highlight in the report. Responses were received from:

DHR (Delaktighet Handlingskraft Rörelsefrihet – Participation Determination Freedom of Movement)

The Swedish Disability Rights Federation

Nätverket mot cancer (Network against Cancer)

Rätten till en värdig död (The Swedish Organisation for the Right to Die in Dignity)

The Swedish Society of Nursing

The Swedish Medical Association

The Swedish Association of Health Professionals