The Final Stages of Life

About the Final Stages of Life

Guidelines to help you consider, discuss and decide

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Preface

Thinking, talking and deciding about the final stages of life is not easy and we prefer to delay anything related to death as much as possible. On the other hand, we also want to stay in control as long as possible. That is only possible if we think about what we do and do not want well in advance and talk about it with our doctors and family members.

In order to make choices and decisions, you need to know what is possible and what is not, what doctors and caregivers can do with regard to your wishes and which rules and regulations they have to comply with. To help you make choices about the end of your life, the NVVE has drawn up this brochure, containing information about the right to refuse treatment, the benefits and necessity of talking to your doctor and family members well in advance, the value of advance directives and what is possible and what is not with regard to requests of euthanasia.

We hope that this brochure will serve as a guide to help you make well-considered choices about the end of your life.

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1 Introduction

It is hard to predict what the last few weeks or months of your life will look like. However, it can be wise to think and talk about it with your family, friends and General Practicioner (GP), because it will help you form a clearer picture of what you would and would not like to happen at the final stages of your life. Knowing what your wishes are and where your limits lie, and telling your friends, family and doctor, can give you great peace of mind.

The NVVE can help you in making certain choices about the end of your life. The prime focus is always on being able to die with dignity. Taking the first step is up to you: thinking about the final stages of your life well in advance. Thinking and talking about dying, however, is not easy. Many people find it a very difficult subject to talk about. Try to break the taboo and start a conversation about your own death, or about the (approaching) death of a loved one.

Perhaps, you already know that you have an illness that you will eventually die of. Maybe, you are old and looking forward to the end, or you have been diagnosed with the early stages of dementia and want to decide yourself what constitutes a dignified end to your life. Even if you are healthy, you can think about which treatment you would and would not want if you are no longer capable of deciding for yourself, such as after an accident. You may also think about whether euthanasia would be an option if you were to develop a serious illness or if dementia would make life unbearable for you.

You could compare thinking about the final stages of your life with making plans for a trip: proper preparations can help you avoid misunderstandings and annoying situations. With this brochure, the NVVE wants to help you prepare for the journey towards the end of your life, even if it is still very far away. Taking the time to think about the end of your life well in advance will contribute to a better quality of life, which, ultimately, is what the NVVE wants to achieve.

Contents of this brochure

Chapter 2 deals with the rights and obligations inherent in the doctor-patient relationship. Doctors are obliged to inform patients about the how, what and why of any intended treatment. Patients have the right to refuse treatment.

Chapter 3 addresses euthanasia laws and discuss how they work in practice, explaining statutory due diligence requirements and practical dilemmas.

Chapter 4 deals with palliative sedation and how it is different from euthanasia.

Chapter 5 discusses what is possible and what is not with regard to euthanasia in dementia patients and concludes with a roadmap for staying in control of the self-chosen end of life.

Chapter 6 contains the current discussion about a 'completed life' and the wish for a self-chosen end of life.

Chapter 7 presents several recommendations that can help you stay in control of your own life and death.

Finally, chapter 8 contains an overview of the (personal) services provided by the NVVE to its members with regard to making choices about the end of life.

2 To treat or not to treat

The body of complex surgical procedures, artificial respiration, tailored medication, new chemotherapy and technical and medical possibilities is constantly increasing. There seem to be limitless ways to extend our lives, but should something really be done simply because it is possible and does every type of medical treatment result in a high quality of life? As a patient, you have a right to help decide.

Talking to your doctor

Every physician is obliged under the Medical Treatment Contracts Act (hereinafter referred to as the law)[1] to explain to the patient any health problems that have been identified, as well as the treatment options, along with their advantages and disadvantages. Talking to your doctor about this is meant to give you a sense of clarity and understanding. It is important to prepare for this talk properly and to write down all your questions in advance. If it is not possible to discuss everything in a single session, you can request a second talk. Of course, you can always ask someone to accompany you. Two minds can understand and remember more than one, and bringing someone along will also give you someone to talk to. You can also ask your doctor to give you the information in writing, allowing you to carefully go through and digest everything at home.

In addition, folders that explain how certain examinations and treatments work can also be very valuable. If you have your doctor's permission, you may also record the conversation, so that you can listen to it again later.

Refusing treatment

The law states that doctors are only allowed to take action if you have given permission for a treatment, examination or another medical procedure. In other words: you have the right to refuse treatment. Only if you have been clearly and properly informed can you decide whether you want something or not. This is also known as *informed consent*. Your doctor is not in

Right to information

Your doctor is obliged to inform you about:

- your health and prospects;
- the nature and objective of an examination, treatment or procedure;
- the consequences and risks of an examination, treatment or procedure;
- possible alternatives for examinations or treatment. In some cases, a patient may not want to be informed. If this has no negative side-effects, the doctor will respect that.

charge of deciding what will happen to you, but they are there to provide advice. You decide whether to undergo treatment or not. You can choose the treatment that has the best chance of success, but you can also decide you do not want treatment at all. If treatment has already begun and you feel that it is not doing enough for you, the treatment has to be discontinued, if that is what you want.

Considerations when deciding for or against treatment

- *Weighing the pros and cons*
  Doctors have the primary goal of 'curing' their patients, which involves treating them. That sounds obvious, but it is not always the best solution. It is best to talk to your doctor to weigh the pros and cons of undergoing treatment.
- *Quality of life*
  Treatment can sometimes have the effect of delaying the end of life, but it may also come with such severe side effects that you can barely enjoy this added time. Sometimes, 'doing nothing' or adopting a 'wait-and-see policy' can lead to higher quality of life.

- *Alleviating symptoms*
  Rather than opting for a treatment that you already know will not cure you, you can ask for treatment that is aimed at relieving symptoms, when this becomes necessary. This is known as palliative care.
- *Don't make hasty decisions*
  Do not be tempted to rush into a hasty decision, but take your time.
- *Experimental treatment*
  In some cases, your doctor may suggest an (experimental) treatment that has not yet been proven to be effective. You are completely free to follow this suggestion, but if you are unsure that you will be able to handle the treatment or expect to see little or no results, you can also refuse, regardless of what the doctor thinks.
- *Pushing back boundaries*
  In practice, it turns out that patients often undergo longer, more intensive treatment than they ever had expected to beforehand. If this is also the case for you, your limits have shifted, hopefully as a result of a conscious decision. Make sure that you always stay in control of what is happening to you.

No life-extending treatment

The law stipulates that competent people (from the age of 12) may not be treated against their will, even if refusing treatment will lead to a quicker death. If you have recorded which treatments you do and do not want in which circumstances in an advance directive (by means of a Refusal of Treatment directive, for instance) these choices, recorded in writing, also apply in situations where you are no longer able to express what you want. A Refusal of Treatment directive lets you refuse life-sustaining treatment, thus remaining in control of the end of your own life. You can indicate whether and how long you want to be treated if you fall into a coma, for instance, and in which circumstances you would only want treatment aimed at combating pain and discomfort. This Refusal of Treatment directive is legally valid, which means that violating your living will is a violation of the law.

No resuscitation

Resuscitation is any act aimed at restarting the heart after cardiac arrest. Not resuscitating is a special type of not treating. Just as you have the right to refuse treatment, you can legally indicate that you do not want to be resuscitated. Resuscitation often occurs in special situations: cardiac arrest typically occurs completely unexpectedly. Bystanders or family members might consider to start ressitation and call the emergency phone number and call for help. Emergency services (ambulance staff, doctors and nurses) will assess the situation and provide suitable assistance on arrival.

The emergency service providers are unlikely to know you and you will probably not be able to communicate your wishes. As such, you will not have the chance to talk to them about your wishes. If someone is unconscious, does not have a heartbeat and is not breathing normally, resuscitation will be started.

However, not everyone wants to be resuscitated. Some people believe cardiac arrest to be a good way to die. It is important that doctors and emergency service providers are informed about your wishes, which you can do by wearing a do-not-resuscitate tag.

The tag will be delivered without a chain.

A do-not-resuscitate tag is an official declaration, worn around the neck on a necklace, bearing a passport photo, signature, name and date of birth. This tag shows that you do not want to be resuscitated if your heart stops. When healthcare professionals or doctors see the tag, they are legally required not to perform resuscitation.

You can order a do-not-resuscitate tag through the NVVE. For more information, visit: **www.nvve.nl/penning**

3 Euthanasia and assisted suicide

Euthanasia means the deliberate termination of life by someone other than the person in question at the request of this person. This may involve a doctor administering a lethal drug (euthanasia) or giving the patient a lethal drink (assisted suicide).
Euthanasia[2] and assisted suicide[3] are illegal and punishable in our country, *unless* carried out by a doctor acting under strict conditions. The exceptional position of a doctor is governed by the Dutch Termination of Life on Request and Assisted Suicide Act (TLR), also known as the Euthanasia Act.

It is legal for a doctor to perform euthanasia or assisted suicide if they comply with the strict conditions laid down in the Euthanasia Act. These legal conditions state that the doctor:

- must be convinced that the patient has made a voluntary, well-considered request to die;
- must be convinced that the patient was faced by unbearable suffering with no prospect of improvement;
- must have informed the patient about their medical situations and prospects;
- must have come to the mutual conclusion with the patient that there is no other reasonable solution for the current situation;
- must have consulted at least one other independent doctor, who has seen the patient and offered their opinion in writing with regard to the required due care;
- must carry out euthanasia or assisted suicide with great care.

These legal requirements are also known as the due-care criteria. The doctor must also report euthanasia or assisted suicide to the municipal coroner and to The regional review committee for euthanasia. This committee will check in retrospect whether a doctor complied with the due-care criteria.

Due-care criteria

1. Voluntary, well-informed request

A request for euthanasia or assisted suicide must be a voluntary and well-considered decision. Voluntary means mean someone's own free will, without any external influence or pressure. Well-considered means that the decision was considered carefully based on sufficient information and a good understanding of the illness in question. Patients must be capable of understanding the consequences of their request.

2. Unbearable suffering with no prospect of improvement

Unbearable suffering is always based on a subjective experience: one person is capable of bearing more pain and suffering than another. Only the patient can judge whether their suffering is unbearable for them. However, the doctor must still be convinced that the suffering is unbearable for the patient, and why. Suffering must also be 'without any prospect of improvement', which means that treatment will not improve the patient's situation within reason. The cause of this suffering may be either mental or physical. Chronic psychiatric disease can ultimately also cause unbearable suffering without any prospect of improvement to the extent that it justifies are request for euthanasia or assisted suicide.

3. Informing the patient

The doctor is obliged to inform the patient accurately about their situation and about the prospects for the future, allowing the patient to make a well-informed request.

4. No other reasonable solution

The doctor and patient must come to the mutual conclusion that there is no other reasonable solution to end or alleviate the patient's suffering. If treatment is still an option – and if it is not too invasive and promises improvement within a reasonable timeframe – it must be attempted. It is up to the patient, however, to decide what constitutes an 'other reasonable solution' and they are free to refuse treatment. However, a patient must always seriously consider proposed treatment. If the patient

immediately refuses treatment without thinking about it first, simply because they want to die, the doctor may feel that there are still alternatives. If, however, the patient takes the proposal seriously and still decides to refuse treatment, this will not stand in the way of euthanasia or assisted suicide.

5. Consulting an independent doctor

The doctor is obliged by law to consult a second, independent (consultant) doctor, who must assess whether the doctor has complied with the due-care criteria. To do so, this consultant will also visit the patient, if possible, before drawing up a report based on their findings. Most likely this consultant will be a SCEN doctor, which stands for Support and Consultation for Euthanasia in the Netherlands. SCEN doctors have been specially trained to assess requests for euthanasia based on the due-care criteria. The consulting doctor does not necessarily have to approve of the request: even in the case of a negative report, a doctor can decide to carry out euthanasia. In that instance, however, the doctor will have not (yet) to explain why the criteria have been met.

6. Careful medical execution

The doctor must act with great care, using the appropriate measures in the right dosage. After administering the lethal drug, the doctor must stay with the patient until they have died, in case any complications occur during the end-of-life process. The doctor must also provide a sound report of the decision-making process and the execution of the request.

Carrying out euthanasia

The professional organizations KNMG [4] (doctors) and KNMP [5] (pharmacists) have drawn up a guideline on carrying out euthanasia and the use of the drugs involved (euthanatics).[6] The doctor carries out euthanasia by administering a drug that will put the patient into a state of deep unconsciousness (coma) by means of an injection or an IV. Afterwards, a muscle relaxant is also administered, which paralyses the respiratory muscles, followed by death.

In case of assisted suicide, the patient will self-administer a lethal drink in the presence of the doctor. The doctor must be present to personally hand the patient the drug and must stay with the patient until the patient dies. If the drink does not lead to the patient's death within a reasonable amount of time, the doctor must still give a lethal injection.

Mandatory reporting

Because all cases of euthanasia involve an unnatural death by definition, the doctor must report the death of the patient to the municipal coroner. The coroner will be given the doctor's report on site, as well as the consulting doctor's report. The municipal coroner will then notify the civil registrar and the district attorney in order to obtain a statement of 'no objections for burial or cremation'. The doctor's and consultant's reports are then forwarded to one of the five regional review committees, who will check whether the due-car criteria were met.
If the committee finds that the doctor has acted with proper care, there will be no further ramifications. The doctor has met all legal conditions and is not punishable.
If, however, the committee finds a shortcoming that the doctor cannot explain when asked, the committee will send its findings to the Public Prosecutor (OM) and the Health & Youth Care Inspectorate (IGJ). They may ask the doctor to clarify any specific uncertainties. If this is still felt to be unsatisfactory, the doctor may be prosecuted by Public Prosecutor's office or indicted by the Health & Youth Care Inspectorate (IGJ).

Request for Euthanasia

Patients have no right to euthanasia or assisted suicide, nor are doctors obliged to comply with the request. Termination of life is not considered part of standard medical conduct. Even if all due-care criteria have been met, a doctor may still refuse to carry out euthanasia, because it is at odds with their view of medical ethics or because euthanasia is in conflict with their philosophy of life or religion, for instance.
Doctors who do not want to carry out euthanasia themselves do, however, have a moral and professional duty to refer you to

a colleague. You are also free to contact another doctor yourself. Your doctor is obliged to hand over your medical file to your new doctor.

Dilemmas

A request for euthanasia made by someone suffering from a severe, painful and life-threatening disease, and for whom treatment is no longer an option, will generally be honoured. This is clearly a matter of unbearable suffering with no prospect for improvement, which means that the request meets the requirements set by the Euthanasia Act. However, approximately one third of all requests for euthanasia or assisted suicide are not honoured. These request are made by people suffering from chronic, but not (yet) life-threatening diseases, people with psychiatric disorders with no prospect for improvement, people who are afraid of the humiliation that comes with dementia (see chapter 5), or from elderly people who are not ill, but are suffering from conditions related to ageing (see chapter 6), for example. The Euthanasia Act offers more options than doctors generally use.

Not in the dying stage

Some people believe that the Euthanasia Act does not apply to people who are not yet dying. This is incorrect. Doctors may also carry out euthanasia or assisted suicide for people who are not in the dying[7] stage. There are incurable, physical diseases, for instance, that progress slowly and after a series of increasingly severe complaints, they ultimately result in death. Examples include muscular diseases and some neurological conditions such as MS (multiple sclerosis), ALS (amyotrophic lateral sclerosis) or Parkinson's disease. If the due-care criteria are met, the doctor need not wait until the dying stage has commenced before carrying out euthanasia or assisted suicide.

Psychiatric disorders

People with a psychiatric disorder such as schizophrenia or a bipolar disorder with no prospect for improvement can experience such mental suffering that it makes them want to end their lives. The Euthanasia Act does not distinguish between physical or mental suffering, but it is true that the suffering of a psychiatric patient is more difficult to interpret. The Dutch Society for Psychiatry (NVvP) has drawn up guidelines for psychiatrists on how to handle requests for euthanasia or assisted suicide made by patients with a psychiatric disorder.[8] Practice has shown that the process of following these guidelines and ultimately coming to a decision can be lengthy.

Written advanced directives

As long as a person is legally competent and is still capable of expressing their wishes, a written request for euthanasia is not necessary. However, when a patient is no longer capable of expressing their wishes, a written request is vitally important. The written request for euthanasia is enshrined in law (art. 2, section 2 of the Euthanasia Act) and replaces the oral request if the person concerned can no longer express their wishes. The request will carry more weight if it has been discussed with a doctor beforehand, and the sooner it is discussed, the better. After all, euthanasia is a joint responsibility of the doctor and patient and doctors too must grow towards the ultimate moment of euthanasia. In addition, many doctors prefer having a request in writing so that they can prove that they carried out euthanasia at the patient's request.

4 Palliative sedation

In practice, the concept of euthanasia is often used incorrectly. Euthanasia always involves the intentional termination of life, leading to an unnatural death.
If a patient dies (earlier than expected) because they did not want to or could not be treated any longer, this is not euthanasia. Palliative sedation, administering strong sedatives and analgesics that will bring the patient into a deep sleep (induced coma), followed by death, is also not euthanasia.

Standard medical conduct

An incurably ill patient may suffer from untreatable symptoms that are unbearable to that patient, such as pain, shortness of breath, fear and confusion. If a patient is expected to die soon (within two weeks' time), the doctor can decide to alleviate their suffering by putting the patient into an induced coma. This is called palliative sedation.
The patient then no longer has to consciously experience their suffering. It is common to stop food or liquids to the patient in this state of deep unconsciousness, which means that the patient will typically die a natural death within a few days.
Palliative sedation is considered standard medical conduct with the goal of alleviating suffering: the goal is not to shorten the patient's life, as it is with euthanasia.
As such, this is not considered life-terminating conduct and palliative sedation is therefore not subject to the Dutch Penal Code, mandatory reporting does not apply, and there is no review process.

Criteria

The doctors' organisation KNMG has drawn up guidelines for performing palliative sedation.[9] They include rules for performing proper palliative care and careful sedation. They are based on practical knowledge and experience and describe the following criteria:

- the patient is incurably ill and is suffering from untreatable symptoms that cause unbearable suffering;

- when there is any doubt about the medical options available to eliminate the symptoms, it is advisable to consult a second doctor, preferably a palliative consultant;
- the patient is expected to die within a reasonably short timeframe, i.e. within two weeks;
- ideally, the patient should be able to discuss the situation and their impending death and grant permission;
- if communication is no longer possible, the doctor must consult with the patient's family or representative, who must grant permission before palliative sedation can be performed;
- after palliative sedation, no more food and liquids will be given;
- a good reporting process is of vital importance. The report must show who made the decision to perform palliative sedation and why, how it was executed, what criteria were used to change the dose of the sedatives and how the effect of the adjusted dose was assessed.

Palliative sedation versus euthanasia

Palliative sedation is a method used to allow someone to die as 'comfortably' as possible. Just like euthanasia, its objective is dying with dignity.

In some cases, a doctor may propose palliative sedation as an alternative to euthanasia. Consider carefully whether you want to switch to palliative sedation and discuss this with your doctor and loved ones, especially if you have previously thought about your final stages of life and would prefer to say goodbye to your loved ones at a time of your choosing. After palliative sedation, you will quickly lose the ability to communicate with those around you, although other bodily functions (breathing, urinary and faecal functions) will remain intact. With palliative sedation, you will die in your sleep, although the sleep before death can last a few days. With euthanasia, you remain in control of your life and death. It must also be said that palliative sedation is not always an option: it is only available to people who are already in the dying stage.

Prevent misunderstandings

It is recommended that you discuss your wishes for the final stages of your life with your loved ones and your doctor, preferably when you are still capable of doing so. If your doctor promises 'not to let you down', ask what they mean by that: will they perform euthanasia if that was what you have decided, or will they carry out palliative sedation?
Clarifying matters well in advance can prevent misunderstandings at your deathbed.

5 Dementia and self-chosen end of life

With an ageing population reaching increasingly higher ages, the number of patients suffering from dementia is also rising rapidly. So too is the number of people diagnosed with dementia who want to retain control over their lives in order to avoid a humiliating end of life. The Dutch Euthanasia Act provides options for euthanasia in case of dementia, but that does not mean that everyone with dementia requesting euthanasia will be assisted.

Stages of dementia

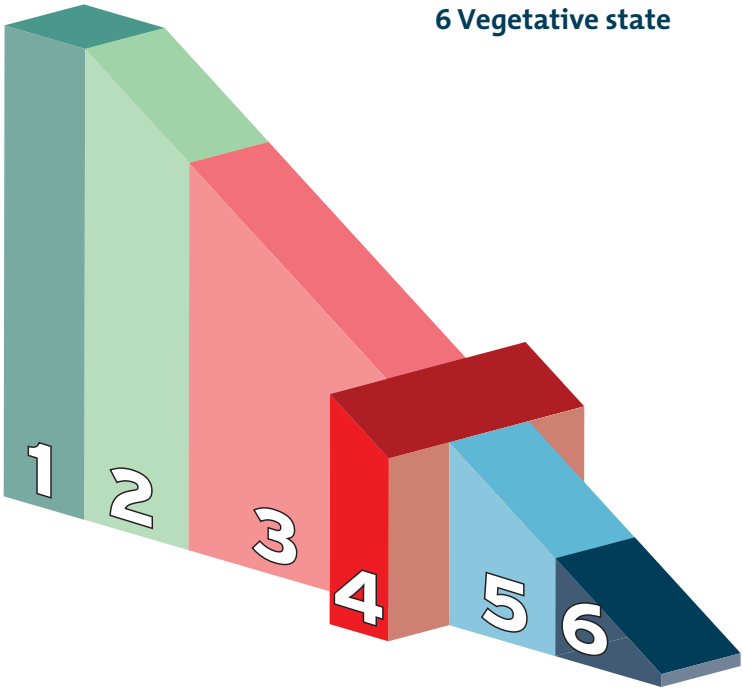
Doctors are still very reluctant to carry out euthanasia or assisted suicide for patients suffering from dementia. The chance of having a request for euthanasia honoured is currently highest during the early stages of the disease. In this stage, (stage 3 in the diagram on page 21) the patient is still legally competent and has plenty lucid moments. In this case, doctors might prefer to carry out euthanasia by having the patient self-administer a lethal drink, rather than through injection. After all, patients will still be physically capable of doing so at this stage and the very act shows they are convinced that this is the right decision.

Unbearable suffering with no prospect for improvement

There is no prospect of improvement for people with dementia, as the disease cannot (yet) be treated and is always irreversible. But is dementia also unbearable? That is for the patient to decide. The Euthanasia Act only requires that the doctor be convinced of the unbearable nature of the suffering.
In recent cases where euthanasia was granted to patients with dementia, those affected indicated early in the disease that the prospect of total despair, loss of control and loss of dignity constituted unbearable mental suffering. They were able to convince their doctor of this, after which their requests for euthanasia or assisted suicide were honoured.

Stages of Dementia

1 No noticeable problems
2 Mild cognitive decline
3 Diagnosed dementia
4 Turning point
5 Advanced dementia
6 Vegetative state



Dementia is an eight-year process, on average, during which time it evolves slowly and irreversibly. The patient's competence declines during this process, which consists of several distinct stages. The line in the diagram shows the downward lifeline, which continues, by definition, to the time of death. The duration of the successive stages depends on the nature and severity of the dementia, as well as the patient's physical and mental condition.

Early diagnosis

New medical developments are making it increasingly easy to diagnose dementia at an early stage. This means that people can already discuss euthanasia with their doctor at an early stage of the disease, so that the patient and doctor can progress towards the moment of euthanasia/assisted suicide together. Nowadays, doctors are more prepared to cooperate with euthanasia for people with dementia, especially if the patient is still competent when the request is made.

Competent

A person with dementia gradually loses the ability to make all decisions themself It is not possible to say in advance exactly when a person will lose their ability to express a verbal request for euthanasia. There are good days and worse days in the process. Usually, it is only possible to say when a person definitively became legally incompetent in hindsight.

Advanced dementia

People often state in written advance directives that they wish to undergo euthanasia when their dementia has reached an advanced stage and they lost their mental descicion making capacity. In practice, doctors have typically been unwilling to carry out euthanasia for patients with advanced dementia. Doctors believe that they can only determine the unbearable nature of suffering when they can still communicate with the patient. However, there are a number of cases in which euthanasia was carried out for patients in the advanced stage of dementia since 2011.

Addendum for requests for euthanasia in case of dementia

If you seriously suspect that you have dementia or are in an early stage of dementia, it is time that you record your wishes with regard to the end of your life in writing on time. It is not possible to determine when a person with dementia will lose their legal competence. It is important to record in writing under which circumstances dementia is unacceptable for you before your competence begins to diminish. The NVVE request for

euthanasia allows you to share your personal thoughts about dementia. This lets you indicate in advance when the limits of a dignified life have been reached. These limits are very personal and are determined by various factors and circumstances. It is important that you not only indicate that you want euthanasia, but also when you want it and which factors contribute to your suffering.

Recommended roadmap

Simply completing the request for euthanasia with your personal explanation is not enough. To increase the chance that your request for euthanasia will be honoured, you must discuss it repeatedly with your doctor or GP well in advance. Your loved ones will also appreciate knowing your wishes. The NVVE has developed a roadmap that can help you strengthen a request for euthanasia in case of dementia. In order to remain in control, you must take the appropriate (precautionary) measures at each stage of the dementia process (see diagram on page 21).

Stage 1

- Complete filling in a Request for Euthanasia. In a personal explanation, you can describe what you consider unbearable and hopeless suffering related to dementia.
- Talk to your family and/or friends about your wishes with regard to the end of your life and ask them to tell you when they suspect that you are becoming more forgetful than usual.

Stage 2

- At the first signs of excessive or increasing forgetfulness, or other symptoms (See www.alzheimernederland.nl) see your doctor and ask to be referred to a specialist for diagnosis.
- Fill in a Request for Euthanasia specifying why the prospect of advanced dementia is unacceptable to you.

Stage 3

- At this stage, you will still be legally competent in most cases. If dementia has been diagnosed, it is recommended

to talk to your GP regularly to keep your request up to date and to stay in control of when euthanasia could be carried out.

- Regularly discuss your wishes for the end of your life with your authorised representative and/or family and friends and ask them to warn you when they believe you have almost reached the limit of losing your legal competence.
- If so desired, you can still amend your Request for Euthanasia at this stage. Use your recent experiences to describe what you do and do not want to experience. This lets you keep your advance directive alive and personal, contributing to its persuasiveness. Doctors consider it very important that patients are still able to communicate and express their wishes. This is demonstrated by the fact that in those situations where euthanasia was deemed to have been performed correctly at an advanced stage of dementia, the patient and doctor had been talking to each other about euthanasia for years before it was ultimately carried out.

Stage 4

- In this stage, the 'red zone', you will have lost almost all your ability to express or explain your wish for euthanasia; your authorised representative or (other) loved ones will have to insist that your doctor grants your most recent request for euthanasia.

Stage 5

- In this stage, you will no longer be competent. Your authorised representative or a loved one will bring your request for euthanasia to the doctor treating you, but the chances are slim that this request will be granted. That is why it is important to make sure the treating physician is aware of your Refusal of Treatment directive and to ensure that it is honoured. Your Refusal of Treatment does not apply to palliative care and other treatment intended to alleviate other symptoms such as fear and pain. If you do not want this treatment either, make sure to specify this in your advance directive.

Stage 6

- Your authorised representative or (another) loved one will ensure that the Refusal of Treatment directive is honoured and that no life-prolonging treatment will be performed, including treatment for complications such as pneumonia.

6 Completed life and end-of-life wish

Doctors and caregivers are dealing with people of highly advanced ages wishing to die increasingly often. They consider their lives to be complete and say that they 'suffer from life'. Based on this fact, they appeal to the Euthanasia Act.
The definition of a completed life used by the KNMG doctors' organisation is:
'Suffering from the prospect of having to continue to live in such a way that there is little or no more quality of life, which leads to a persistent desire to end their lives, without the main cause for this being a somatic (physical) or mental condition.'

Complex combination of factors

People who feel that their life is completed often have a number of reasons for preferring to end their lives, such as:

- loss of independence and personal dignity;
- dependence on professional care and/or care from family members and loved ones;
- loss of status and control over one's own life;
- loss of one's social network as a result of the death of a partner and/or children, friends and neighbours;
- loss of meaning and purpose;
- detachment from society (connection with people, material matters and today's world no longer exists);
- fear of the future;
- no prospects for the future.
- non-life-threatening conditions, such as physical decline (diminished walking, seeing and hearing ability, fatigue, listlessness, incontinence), resulting in the loss of activities that make life worthwhile.

Doctors will never be able to carry out euthanasia based on a 'completed life' alone, because there must always be a medical reason for euthanasia. However, many people who find their lives to have been completed have to deal with a large number of age-related symptoms, which may form a valid reason to request euthanasia.

Some people may be able to or want to continue to live while suffering from several age-related symptoms, whereas others may come to the conclusion that suffering from many age-related symptoms is too unbearable and that ending their life is therefore the best option. It is always a highly personal decision and never a generally valid judgement.

A range of age-related symptoms—such as function loss and loss of dignity—may, in some cases, serve as grounds for euthanasia or assisted suicide. While each condition on its own may still be manageable, many people face a combination of problems simultaneously. This accumulation of ailments, often referred to as a 'stacking' of age-related conditions, can gradually make life feel increasingly burdensome.

Room in the law

The Euthanasia Act is explicitly not intended for issues concerning a completed life, as was confirmed in the Brongersma ruling (2002), here the Dutch Supreme Court said explicitly that the Euthanasia Act only applies in case of medically-definable physical of mental disease. However, this does not completely rule out euthanasia for people who feel they have completed their life. If you feel you have completed your life and suffer from age-related symptoms, there may me options for you. In 2011, the KNMG created some room when it indicated that an accumulation of age-related symptoms, including loss of bodily functions and dignity, may serve as grounds for euthanasia or assisted suicide.

Talking about the approaching end of life

When growing older, it is very important to talk to your GP regularly about your health and how you perceive your quality of life. Your doctor is aware of the medical options available to help ensure that your life remains acceptable and you can indicate what you believe to be acceptable. It is up to you to decide on what is and is not acceptable. If you think that euthanasia might be an option for you in the future, talk about it. Talking about it creates clarity.

Refusal of Treatment directive

People who are aware that they are the end of their lives and are experiencing the limitations this entails, but do not necessarily want to end their lives yet, can draw up a Refusal of Treatment directive and/or wear a Do-Not-Resuscitate tag. In a personal explanation to the Refusal of Treatment directive, you can indicate which treatment you would like to receive under which conditions and which you would not.

If you wish, you can also refuse any kind of medical treatment. In that case, you are still entitled to guidance and treatments that help alleviate discomfort and symptoms. In a personal addendum about a 'completed' life to the Refusal of Treatment directive, you can also refuse any medical conduct because you consider your life to have been completed. By signing the directive, you indicate that you are 'done living' and that you would like to seize any opportunity to die, including treatable conditions.

Suicide

The option for people with a real desire to end their lives and whose doctors refuse to help them with euthanasia, is 'suicide'. In the Netherlands, (attempted) suicide is not punishable.
However, encouraging suicide, aiding suicide and providing means to commit suicide are punishable. Providing information and talking about 'a self-controlled, dignified death' is permitted and not punishable.
For some older people who no longer wish to live, voluntarily stopping eating and drinking (VSED) is a conscious decision made with the intention to die in a dignified and self-directed manner. This option is legal and does not require approval from a physician, but proper medical guidance is crucial. With good care and support, the dying process can be made more bearable and peaceful. Without such support, especially for those who are still physically healthy and have a strong appetite, it may become long, uncomfortable, and emotionally difficult.

What happens in the body during VSED?

When a person stops eating and drinking, the body no longer receives enough fluids or energy. As a result, it begins to break down fat and muscle tissue to survive. This leads to weakness and physical decline.

Without fluids, the body becomes dehydrated. The kidneys, which rely on fluid to remove waste products from the blood, can no longer function properly. Within a few days, this can cause confusion or drowsiness, and ultimately, death due to kidney failure.

Is VSED a peaceful death?

Most people who choose VSED die in a relatively gentle way. However, it is not always free from discomfort. Symptoms such as thirst, pain, or confusion are common. Fortunately, these can usually be managed well with the right medication and care. That's why good medical and emotional support is essential throughout the process.

7 Summary

Take control

You play an important role in retaining control over the final stages of your life. This brochure describes your options, along with the associated legal, ethical and social considerations. Below is an overview of things you can do to contribute to the realisation of the dignified end of your life.

Talk to your doctor and family

It is important that you talk about the end of your life and your wishes well in advance. You can talk to your loved ones, your care provider and your doctor. By talking about your questions, expectations and wishes well in advance, you can prevent the final stages of your life from going differently than you would want.

Draw up an advance directive

As long as you are capable of communicating directly with your doctor, you can influence how your disease is treated and how you will die. The situation changes if you lose legal competence and find yourself in a state where you are no longer able to express what you want. You may suffer from dementia or fall into a coma, for instance. However, it is still possible to let others know what you want in such a situation by recording all your medical wishes with regard to treatment or your end of life in an advance directive. An advance directive is by no means a 'permanent contract' nor a garantueed access to euthanasia: as long as you remain competent, you can always deviate from what you have written: your word outweighs your written advance directive.

- *Refusal of Treatment directive*
  In a Refusal of Treatment directive, you can stipulate the circumstances under which you do not wish to undergo certain medical treatment. The law states that doctors and healthcare providers are, in principle, obliged to comply with a written Refusal of Treatment directive.

- *Power of Attorney*
  You can also choose to appoint your authorised representative in writing. With a Power of Attorney, you can appoint someone to act on your behalf when you are no longer able to express your wishes. It is very important that you appoint someone who you believe will represent your interests in accordance with your wishes.
  You could choose your partner, one of your children or your brother or sister, but you can also appoint an 'outsider', such as a good friend. The wishes expressed by your authorised representative will be considered to be your wishes. You need not notarise the Power of Attorney, but you do have to inform your GP and provide them with a copy of the Power of Attorney.

- *Request for Euthanasia*
  In a Request for Euthanasia, you can stipulate under which circumstances you want your doctor you end your life. In contrast to a Refusal of Treatment directive, much like an oral request, a written Request for Euthanasia cannot be enforced by law; doctors are not obliged to comply with your request. Nevertheless, it is recommended that you do draw up a written Request for Euthanasia, irrespective of whether you will be requesting euthanasia soon or in the future. In the former situation, the written request serves as 'proof' that the patient was euthanised at their own request. In case of a request for a future situation in which the patient may no longer be competent, a written request serves as a replacement for an oral request. The Euthanasia Act stipulates that a written statement drawn up in advance constitutes a valid request and can be used as a guideline for further action. It remains a request, however, so your doctor is not obliged to grant it. The more specific your written request, the more support it will provide during the doctor's decision-making process.

Always discuss your advance directive with your doctor or GP. This lets your doctor know what you want and lets you know what your doctor can do for you. It is also important (but not legally required) to notify your family and loved ones of your wishes and advance directive(s).
For more information, you can read the NVVE brochure *Toelichting bij de wilsverklaringen* (More information about advance directives).

Keep your advance directives up to date

According to the law, signed advance directives retain their legality irrespective of how much time has passed. Nevertheless, the NVVE recommends keeping your advance directive up to date. It is therefore important, especially with regard to a Request for Euthanasia, that you continue to speak to your doctor and that you keep your advance directive up to date, amending it as often as you and your doctor deem necessary.

Have your interests represented

If you are no longer able to communicate, your doctor will be obliged to discuss your medical condition and any treatment with an authorised representative. Your spouse/life partner is first in line. If you do not have a spouse or life partner, your family is next in line: a parent, child, brother or sister, in no specific order of precedence.

8 NVVE Services

The NVVE is a fast-growing association that represents its members' interests. The NVVE strives to make it possible for everyone to die in a dignified manner. We employ 34 people at our headquarters in Amsterdam, in addition to 144 consultants who work all over the country. NVVE activities and services may help you make certain decisions and realise your wishes in the final stage of your life. As an NVVE member, you will have access to the following services:

- **Advanced directives**

You can order digital (from the website) and paper advance directives from the NVVE, which come pre-completed with your personal information. In these advance directives, you can record your wishes for the end of your life, so that they can be made known when you are no longer capable of doing so yourself. You can also draw up an advance directive online.

- **NVVE Advice centre**

Members who have questions about a personal situation, about a disease or their desire to end their life, can contact the NVVE to request a personal meeting. In this personal meeting, NVVE consultants can answer questions such as:

- What should I write in the personal addendum to my advance directives?
- Can I refuse treatment?
- Do I need an authorised representative and who can I ask?
- How should I discuss my wish for euthanasia with my doctor?
- What are the conditions for euthanasia?

You can request a meeting by calling +31 (0)20 620 06 90. If a member is not capable of contacting the NVVE, their loved ones can contact us on their behalf. Depending on the nature of the question, you can then have personal talk over the phone or during a house call.

- **Advance directive consultations**

The NVVE holds weekly consultations in several locations throughout the Netherlands, which NVVE members can attend (for free) with any questions they may have about advance directives. For more information about the options available, go to www.nvve.nl/spreekuren. You can also make an appointment there.

- **Information meetings and briefings**

The NVVE offers lectures, webinars and meetings about end-of-life choices. Topics include advance directives, dementia, completed life and age-related conditions. NVVE also shares information at exhibitions, symposia and workshops.

- **Relevant**

'Relevant' is NVVE's magazine, which covers current developments and provides background information about (self-chosen) end of life. The magazine is published quarterly and is free for NVVE members.

- **Brochures**

When you receive your advance directives, you will also receive the 'More information about advance directives' brochure. The NVVE also publishes other brochures, which members can order or download at www.nvve.nl.

- **Newsletter**

Everyone can subscribe to the weekly digital newsletters, which include announcements of and reports on current events.

- **The do-not-resuscitate (DNR) tag**

The NVVE issues the do-not-resuscitate (DNR) tag. This is a treatment refusal (and therefore also an advance directive/ living will) that states you do not want to be resuscitated if your heart stops. The tag is available to everyone, but members pay a reduced price. More info: www.nvve.nl/penning.

Sign up as an NVVE member

You can sign up to the NVVE via the website. You can also sign up as a member by completing the registration form enclosed in the general NVVE information brochure. Send the completed form in a sealed envelope to NVVE, Antwoordnummer 347, 1000 SL Amsterdam (no stamp required).

Membership costs € 28,00 per person per year. On AOW or benefits? You can request a reduced fee when registering.

After signing up, you will receive your membership number, which you can use to register at www.nvve.nl and grants you access to the members' section of the NVVE website, where you can find the digital advance directives, among other things.

Questions?

If you still have questions, please call the NVVE offices during office hours or visit our website.

NVVE
Phone: +31 (0)20 620 06 90
Website: www.nvve.nl

Gifts, regular donations and bequests

There are many ways to support the NVVE, including one-off donations, regular donations and bequests. Any donations are deductible from income tax. This also applies to the membership fee. The NVVE is an acknowledged charitable institute, which means it is exempt from inheritance tax for bequests and legacies.

Donations

There are also other ways to support the NVVE.
For more information, visit www.nvve.nl.

Footnotes

1 The Medical Treatment Contracts Acts (WGBO, 1995) is included in the Dutch Civil Code and formulates the caregiver's obligations towards a patient.

2 Criminal Code, Article 293, section 1: anyone who deliberately ends another person's life at his explicit and severe wish, will be punished with a maximum imprisonment of 12 years or a maximum fine of € 78,000.

3 Criminal Code, Article 293, Section 1: anyone who deliberately assists another person with suicide or provides him with the means to do so, will – if suicide is successful – be penalised with a maximum imprisonment of three years or a maximum fine of € 19,500.

4 Royal Dutch Medical Association (KNMG)

5 Royal Dutch Pharmacy Association (KNMP)

6 Guideline 'Performing euthanasia and assisted suicide' KNMG/KNMP, 2012

7 A person in the natural stages of dying is expected to die within one to two weeks.

8 www.nvvp.nl/publicaties.

9 KNMG Guideline 'Palliative sedation' (2009).

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