Guide

Caring for people who stop eating and drinking to hasten the end of life

Colophon

Caring for people who stop eating and drinking to hasten the end of life is a guide of the Royal Dutch Medical Association (KNMG), Dutch Association of Physician Assistants (NAPA), the Dutch College of General Practitioners (NHG), the Dutch Internists Association (NIV), the Dutch Society for Clinical Geriatrics (NVKG), the Dutch Society for a Voluntary End of Life (NVVE), the Dutch Nursing Society (V&VN), the Society of Elderly Care Physicians (Verenso)

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Part 1 General information

1. Introduction

1.1 History

Studies by Chabot (2007) and Van der Heide (2012-1) show that in 0.5-1.7% of all deaths in the Netherlands people voluntarily stopped eating and drinking to hasten death. Sometimes it concerned people with a death wish whose euthanasia request had been rejected, but in other cases people who had fundamental or emotional objections to euthanasia, or did not want to burden the doctor with it. Others felt it was their own responsibility to achieve a self-chosen end of life.

These data, societal developments (such as an increased focus on the self-chosen end of life) and reports from doctors prompted the Royal Dutch Medical Association (KNMG) to set up a committee in 2013. The committee was tasked with drafting "a guideline to enable doctors and nurses to properly prepare and guide patients, and to initiate or continue adequate palliative care when patients have made the choice to voluntarily refrain from eating and drinking to hasten the end of life".

In 2014, the KNMG published the guide 'Caring for people who voluntarily refrain from eating and drinking to hasten the end of life'. The boards of the Dutch College of General Practitioners (NHG) and the Dutch Association of Elderly Care Physicians (Verenso) agreed to the guide. The Dutch Society for Clinical Geriatrics (NVKG) and the Dutch Nursing Society (V&VN) authorized the guideline.

1.2 Review of the guide

In 2021, following a needs assessment in the agenda committee of the KNMG/IKNL¹, the KNMG decided to revise the guide. To this end, a committee was formed with members mandated on behalf of various professional and scientific associations: the Dutch Association of Physician Assistants (NAPA), the Dutch College of General Practitioners (NHG), the Dutch Internists Association (NIV), the Dutch Society for Clinical Geriatrics (NVKG), the Dutch Society for a Voluntary End of Life (NVVE), the Dutch Nursing Society (V&VN), the Society of Elderly Care Physicians (Verenso) and the Royal Dutch Medical Association (KNMG).

A sounding board group was also formed with representatives of the Association of Hospice Care Netherlands (AHzN), the Catholic Association of the Elderly-Brabant (KBO-Brabant), the Catholic Association of the Elderly/Protestant Christian Elderly Association (KBO-PCOB), the Dutch Society of Cardiology (NVVC), the Dutch Patients Federation, the national expertise center Pharos and (in a personal capacity) prof. Dr K.C.P. Vissers, anesthaesiologist and professor of Pain and Palliative Medicine (Radboudumc).

1.3 Working method of the committee and accountability

The committee met five times between April 2022 and March 2023. In addition, a systematic literature review was conducted by a literature reviewer to obtain as complete a review as possible of recent literature on voluntarily stopping eating and drinking to hasten the end of life (see annex 2).

¹ The agenda committee advises on prioritization, planning and coordination of palliative care guidelines. The committee consists of representatives of relevant professional and scientific associations and the Patient Federation of the Netherlands.

Relevant literature was reviewed and draft texts were prepared. The draft texts were submitted to the sounding board group for comments twice, in August 2022 and October 2022. The committee reviewed all draft texts, modified them if necessary and adopted them. After that, in May 2023, the draft guide was submitted to the members of the sounding board group and at the same time presented to the professional and scientific associations of the committee members for comments. The committee then reviewed and incorporated all comments. The commenters received feedback prior to authorization.

The content of the guide was adopted on October 10, 2023. Subsequently, the guide was sent to the professional and scientific associations of the committee members for authorization/approval/consent. The guideline was approved/authorized/consented on December 5th, 2023. Finally, the federation board of the KNMG adopted the revised guideline on December 14th, 2023.

1.4 Target group and meaning of the guide

The guide is primarily intended for doctors, physician assistants, nurse specialists and nurses. This guide enables them to properly prepare and care for patients, and to initiate or continue adequate palliative care for them.

The guide can also be read and used by other healthcare providers, volunteers, patients and relatives. However, the choice of words and terminology are not tailored to this. Relatives can find the information to best care for the patient during the process of voluntarily stopping eating and drinking in the book 'Uitweg' (Chabot 2022) (in Dutch). Furthermore, the NVVE's brochure 'Voluntarily stopping eating and drinking' (in Dutch) (2022) can also be used, as well as the podcast with an interview with Eva Bolt. (in Dutch)

This guide is not intended for guiding hunger and thirst strikers. There are also other options for a self-chosen end of life, but these are not elaborated upon in this guide.

1.5 Changes compared to the 2014 guide

Compared to the 2014 guide, the following substantive changes have been made:

- The committee changed the title of the guide to 'Caring for people who stop eating and drinking to hasten the end of life'.
- The guide is divided into three parts:
 - 1. General information

2. Caring for people who voluntarily stop eating and drinking to hasten the end of life

- 3. Stopping the offering of food and drink to incompetent patients² with dementia
- For 'voluntarily stopping eating and drinking', the abbreviation VSTED³ is used.
- Chapter 1 describes the history of the guide and the course of events after the previous version of the guide was published. Nursing specialists and physician assistants are added to the target group. Two recently published guidelines on VSTED are also briefly described.

² The term 'incompetent' as used further in this guide, refers to patients who are decisionally incompetent with regard to the decision to stop eating and drinking.

³ The Dutch guide uses the term BSTED, which is the Dutch acronym for *Bewust Stoppen met Eten en Drinken* (Deliberately Stopping Eating and Drinking). As the English literature uses the term VSTED, this acronym is used in the English translation.

- Chapter 2 explains why the title of the guide has been changed. It also discusses offering food and drink versus artificial administration of nutrition and fluids, foregoing treatment (both relevant to Chapter 6) and advance care planning.
- The literature was updated using the systematic literature review (see Annex 2). The empirical data in Chapter 3 have been updated accordingly. For Chapter 3, a summary has been added at the beginning of the chapter.
- Chapter 4 elaborates on the legal and ethical backgrounds of VSTED and discusses in more detail the relationship between VSTED and suicide. A summary has also been added. The section on decision-making in chapter 4 of the previous version of the guide (section 4.5) has been moved to chapter 5 of the current version. Furthermore, advance care planning and offering food and drink versus administering nutrition and fluids are discussed.
- Chapter 5 deals explicitly with decision-making. A summary has been added at the beginning of the chapter. VSTED is no longer advised against in patients younger than 60 years, because several cases have been described that show that people younger than 60 years can also end their life by stopping with eating and drinking. Furthermore, the content of chapter 5 has been adjusted in detail.
- Chapter 6 (Stopping the offering of food and drink to incompetent patients) has been completely rewritten compared to the corresponding chapter in the previous guide. It focuses on people with dementia. It also discusses situations in which there is no defensive behaviour. The reasoning for when food and drink should and should not be offered is elaborated upon in more detail. A summary has been added at the beginning of the chapter.

1.6 Reading the guide

Chapter 2 contains a description of the relevant features and concepts in this guide. Chapter 3 pays attention to empirical data. Chapter 4 discusses advance care planning and elaborates on legal and ethical aspects. Chapter 5 describes decision-making, care by professionals, volunteers and relatives in patients who voluntarily stop eating and drinking. Chapter 6 describes how to deal with stopping offering food and drink in incompetent patients with dementia. To the (extended) chapters 3, 4, 5 and 6, summaries have been added at the beginning of the chapter.

The committee has chosen to refer to 'she' and 'her' wherever the gender of a patient, relative or healthcare provider is not clear. Thus, where 'she' or 'her' is mentioned, 'he', 'that', 'them' or 'his', 'their' can also be read, respectively.

1.7 Other guidelines on VSTED

A US guideline on VSTED was published in 2023 (Wechkin 2023). The authors indicate in their article that this guideline is partly based on the 2014 KNMG guide, but adapted to the US situation, especially with regard to legislation, healthcare organization and attitudes towards end-of-life care.

Gruenewald (2018) provides practical suggestions and a checklist for caregivers and nursing home staff in the United States dealing with patients who want to opt for VSTED. The advice in the above guidelines is not essentially different from that in the current guide. The focus of the US guideline is on patients with life-threatening disease with a prognosis of months to several years. The guideline considers death after VSTED a natural death.

Stopping offering food and drink to incompetent patients is beyond the scope of both guidelines.

The committee is not aware of any other guidelines regarding VSTED, nor is it aware of any guidelines regarding stopping offering food and drink in incompetent patients with dementia.

2. Characteristics and definitions

This chapter describes the relevant characteristics and concepts in the field of stopping (offering) eating and drinking.

2.1 Patients

This guideline refers, on the one hand, to people who do not have a classifiable disease and, on the other hand, to patients who are in a condition that a doctor classifies as a disease or combination of diseases and complaints. People who do not have a classifiable disease, but at some point involve the doctor, physician assistant, nursing specialist or nurse in (intending to) voluntarily stop eating and drinking to hasten the end of life, then become 'patients' in the context of the treatment agreement as described in the Dutch Medical Treatment Agreement Act (WGBO). Action 1.5 This guide further refers to patients.

2.2 Voluntarily stopping eating and drinking to hasten the end of life

The description 'voluntarily stopping eating and drinking to hasten the end of life' refers to the decision made by a person to stop eating and drinking for the purpose of hastening the end of life. This includes deliberately refusing food and drink that is offered and deliberately refusing artificial administration of nutrition and fluids. This is defined in the literature as 'the act of a competent person who voluntarily and deliberately decides to stop eating and drinking with the primary goal of hastening death because of persistent unacceptable suffering' (Ivanovic 2014). The distinction from hunger strike is that this does not involve the intention to die.

In the English-language literature, the term 'voluntar(il)y stopping eating and drinking' is mostly used (Gruenewald 2018, Ivanovic 2014, Lowers 2021-1, Quill 2018-1, Quill 2022). For this, the abbreviation 'VSED' is also used. Other terms used are 'voluntary refusal of food and fluids' (Quill 2000-2, Ganzini 2003, Harvath 2004, Rady 2011, Schmidhuber 2019), 'voluntary dehydration' (Jacobs 2003), 'voluntary cessation of eating and drinking' (Gruenewald 2020, Radbruch 2017), 'volitional death by starvation and dehydration' (Baracos 2017) and 'patients refusal of hydration and nutrition' (Bernat 1993).

This terminology draws heavily on US literature, culture and jurisprudence. German-language literature from Germany, Switzerland and Austria uses the terms 'bewusster und freiwilliger Verzicht auf Nahrung und Flüssigkeit, um das Sterben zu beschleunigen' (Fleichtner 2018-1 and 2018-2) and 'Sterbefasten' (Simon 2015).

The committee maintains the 2014 committee's choice to include 'deliberately' in the Dutch description, as this expresses that it is a deliberate choice made by the person herself. For this reason, the committee does not use terms such as 'refuse' or 'withhold'. Nor does the committee use the term 'starvation', because very different meanings are attached to this.

The committee has chosen to replace the term 'refrain from' with 'stopping' in the title of the guide. This is more in line with speech in practice and terminology in the international literature. In the English translation the abbreviation VSTED (acronym for Voluntarily Stopping Eating and Drinking) has been chosen (see footnote 3).

⁵ Depending on the situation and the nature of the decisions, treatment decisions can also be made independently by physician assistants or nurse specialists.

⁴ See art.7:446 paragraph 1 Civil Code (BW), part of the Medical Treatment Agreement Act (WGBO).

VSTED is substantially different from gradually reducing food and drink intake as part of a terminal illness process or due to old age, because in those situations it is not an active choice of the patient.

For the sake of readability the addition 'to hasten the end of life' will be omitted in the remainder of this guide.

2.3 Stopping the offering of food and drink in incompetent patients

It is conceivable that the responsible caregiver decides to stop offering nutrition and fluids to an incompetent patient on the basis of a written advance directive, documented previous verbal expressions of will by the patient, or the opinion of the patient's representative and relevant caregiver(s). This mainly concerns patients with dementia. See also chapter 4 and chapter 6 on this. In such cases, at the time of the decision to stop offering food and drink, there is no **voluntary** stopping of eating and drinking by the patient himself.

A patient should be presumed to be competent until proven otherwise (KNMG 2004, p. 92). Mental capacity may fluctuate over time and may vary by decision or action domain. The following aspects characterize a patient who is capable of exercising his or her will with regard to a particular decision:

- 1. making a choice known;
- 2. understanding relevant information;
- 3. realizing and appreciating the significance of the information for one's own situation;
- 4. logical reasoning and including the information in considering treatment options.

In these aspects, the patient's cognitive skills are dominant. The guide 'Decision-making skills and decision-making capacity: supporting and assessing' by the Foundation for Quality Impulse Long-Term Care (SKILZ) advocates including the patient's emotions and values in the determination of capacity.

The guideline uses ten criteria for competence: 1) understanding information, 2) gaining insight into one's own situation, 3) looking for options for action, 4) considering options for action, 5) estimating the consequences of preferred option(s) for oneself, 6) estimating the consequences of preferred option(s) for others, 7) motivating choice in a comprehensible and understandable way, 8) motivating a choice from goals and values, 9) being free from compelling influences from within, and 10) being free from external compelling influences.

Incompetent patients are patients who 'cannot be considered capable of a reasonable appreciation of their interests in relation to a decision or situation under consideration' (KNMG 2004, p. 91). Incapacity refers to a patient's decision-making ability depending on the choices or decisions made in a given context. A step-by-step plan has been developed for testing competence (see KNMG 2004). The SKILZ manual Decisiveness and Willingness also provides a step-by-step plan.

2.4 Offering food and drink versus artificially administering nutrition and fluids Relatives and/or caregivers⁶ may play a role in the patient's eating and drinking. A distinction should be made between:

providing or putting down food and drinks;

⁶ In this guide, the committee uses the term healthcare provider(s) as a collective term for doctors, physician assistants, nurse specialists, nurses and carers.

- helping patients eat and drink if they cannot do so themselves for physical or cognitive reasons:
- the artificial administration of nutrition and/or fluids through a nasogastric tube, PEG or PRG catheter or by the subcutaneous (fluid only) or intravenous route. This is reserved for authorized healthcare providers. The decision to start artificial administration of nutrition and/or fluids is made by the doctor. Discontinuation of artificial nutrition and/or fluids may be a decision by the physician, but may also be based on the patient's wishes. Nurses may have a role in administering nutrition and fluids via a tube or infusion, provided they are authorized and competent under the Dutch Individual Healthcare Professions Act (Wet BIG). This also applies to the insertion or removal of the nasogastric tube or drip by a nurse, which is necessary for this purpose.

2.5 Refraining from treatment

Patients always have the right to decline (specific aspects of) treatment, nursing and care. They are entitled (under the WGBO) to receive information from the doctor about their medical condition, prognosis and treatment options in order to make this decision well-considered. On the basis of this information, patients give or withhold consent to healthcare providers to treat, nurse or care. If (competent) patients do not give consent, healthcare providers may not provide treatment, nursing or care.

2.6 Palliative care

Palliative care is care that improves the quality of life of patients and their relatives dealing with a life-threatening condition or frailty, by preventing and relieving suffering, through early identification and careful assessment and treatment of pain and other problems of a physical, psychological, social and spiritual nature. During the course of the disease or frailty, palliative care is concerned with maintaining autonomy, access to information and possibility for making choices (IKNL/Palliactief 2017, p. 9).

Because consistent stopping eating and drinking irrevocably leads to death, the committee considers the care for the person making this decision to be a form of palliative care, even if there is no immediately life-threatening illness at the time the decision is made.

2.7 Advance care planning

Advance care planning (ACP) enables people who are able to exercise their will to identify values that are important to them, think about the meaning and consequences of any serious illness, formulate goals and preferences for future medical treatments and care, and discuss these with relatives and healthcare providers (see the Guideline Care Planning) (KNMG 2021-3, Rietjens 2017). Hereby, people can record any preferences and revise them if necessary. They can also appoint a representative, who can make decisions if the patient has become incompetent (see section 2.3). In this way, a person's preferences can be taken into account at a time when they are unable to make decisions themselves.

Advance care planning is discussed in chapter 4, with a particular focus on written advance directives and previous oral expression of will regarding stopping eating and drinking.

2.8 Palliative sedation

Palliative sedation is "the deliberate lowering of a patient's consciousness in the last phase of life with the aim of relieving suffering" (Palliative Sedation Guideline). The aim of palliative sedation is to relieve the patient's suffering by lowering consciousness. Palliative sedation can

be used continuously, intermittently or once for a short period of time. The role of palliative sedation in VSTED is discussed in section 4.4 and section 5.8.6.

2.9 Division of responsibility and directional treatment

In any care trajectory, it is essential that the responsibilities of the various health care providers are clearly divided and assigned. If necessary, it is explicitly agreed and described who is responsible for what. This should preferably also describe how decisions are made and the escalation procedure if the usual way of decision-making does not lead to a solution. In such an escalation procedure, one can, for example, choose to give one of the involved healthcare providers a decisive vote or to have the decision taken at another (higher) level.

So many different healthcare providers and disciplines may be involved in palliative care that it may be necessary to designate a single healthcare provider to take the lead, known as the directing practitioner. However, a directing practitioner only needs to be appointed if the number of healthcare providers involved and the complexity of the care make this necessary.

In any case, the directing practitioner ensures that:

- the continuity and consistency of care provided to the patient are monitored and that treatment adjustments are initiated where necessary;
- there is an adequate exchange of information and sufficient consultation between the healthcare providers involved in the treatment;
- there is a point of contact for the patient or his representative and/or relatives for timely answers to questions about the treatment. The directing practitioner does not have to be the point of contact and be able to answer all questions herself, but should be able to refer to someone who can provide those answers.

The directing practitioner is usually a BIG-registered healthcare provider⁷, but not necessarily. She must, however, have the required capacity for the tasks of the directing practitioner, as described above, focused on the palliative care under discussion. A directing practitioner is not necessarily always a doctor. Depending on the circumstances and the healthcare sector, a healthcare provider from another professional group, e.g. a healthcare psychologist, a physician assistant, a nursing specialist or a nurse or other healthcare provider may also fulfil the role of directing practitioner.

The starting point is that each healthcare provider involved in a patient's treatment has and maintains her own professional responsibility towards that patient. It is important that the patient is informed about who is the directing practitioner and - if different - who is the point of contact. It depends on the situation which healthcare provider makes the decisions. If a directing practitioner is appointed, it does not have to be the one who makes the decisions.

This guide further refers to the 'responsible caregiver'. In the home situation, this will often be the general practitioner, in the nursing home the elderly care specialist and in the hospital the medical specialist.

⁷ The purpose of the Healthcare Professionals Act (Wet BIG) is to promote and monitor quality in health care. The Act also protects patients from careless or incompetent treatment by a healthcare professional. The Dutch BIG register is one of the tools for implementing the Healthcare Professionals Act.

3. Empirical data on VSTED

3.1 Summary

- VSTED to hasten the end of life plays a role in 0.5-1.7% of all deaths in the Netherlands.
- More women than men choose for VSTED. Many patients are older than 80 years.
- In about 60% of cases, there is a serious physical illness and in 12-30%, (early) dementia. In about 25% of cases, there is no serious physical or psychiatric illness, but there is an accumulation of age-related complaints and/or 'completed life' issues.
- Many considerations play a role in the decision to stop eating and drinking: mainly physical symptoms (especially fatigue and pain), suffering from life, completed life, having no purpose in life, dependence, disability and loss of dignity.
- In 19-45% of cases, the patient had made a request for euthanasia which was rejected or not carried out.
- Qualitative research from the Netherlands suggests that the decision to stop eating and drinking is regularly reversed by the patient. Retrospective data from an American study suggest that 13% of patients go back on this decision.
- Most patients die within 1-3 weeks. If patients continue to drink, the process takes longer.
- The course in terms of patient symptoms and burden has not been systematically described. Global retrospective studies in relatives and healthcare providers and case histories indicate a dying process that is usually associated with relatively few symptoms and little suffering, if appropriate care is given.
- After stopping eating, the feeling of hunger disappears after a few days, provided no carbohydrates are ingested.
- Good oral care is essential to reduce the feeling of thirst or dry mouth as much as possible.
- A Dutch study indicates that during VSTED palliative sedation is started in 28% of cases.
- VSTED can be a great burden for relatives/caregivers, as they may feel that they have to defend the patient's choice to those around them, feel responsible for a good course, and at the same time may have a lot of difficulty with their loved one's decision. They often seem to experience insufficient support from professional caregivers.
- There seem to be interindividual and international differences in healthcare providers' attitudes towards stopping eating and drinking. Most healthcare providers do not experience moral objections. Care for patients who stop eating and drinking is sometimes perceived as 'passive euthanasia' (omission of a life-extending act) or assisted suicide. The care is sometimes perceived as difficult and burdensome. In Switzerland, 97% of healthcare providers respect the patient's choice and 70-75% consider it a dignified form of dying. Just under half would recommend it to a patient in case of a death wish.
- To properly guide a patient through the decision-making, preparation and possible implementation of VSTED, it is important to adapt to the patient's personal situation.

3.2 Introduction

This chapter first describes the (patho)physiological and clinical consequences of stopping eating and drinking. It then presents data from the literature on the practice of voluntarily stopping eating and drinking. These include descriptive studies (Bolt 2015-1 and 2015-2⁸, Chabot 2007, Eppel-Meichlinger 2021, Ganzini 2003, Hagens 2021, Harvath 2004, Van der Heide 2012-1 and 2, Hoekstra 2015, Lowers 2020-2, Stängle 2020-1, 2020-2, 2021-1, 2021-2 and 2021-3, Shinjo 2017) and publications describing case histories (Van Aarnhem 2011-1

⁸ Bolt 2015-1 and Bolt 2015-2 refer to the same study. In the following, only Bolt 2015-1 will be referred to.

and 2011-2, Ann 2016, Berry 2009, Brown 2016, Douglas 2016, Eddy 1994, Greenlaw 2016, Gruenewald 2018, Henry 2016, Jacobs 2003, Jansen 2002, Jose 2016, Koopmans 2004 and 2012, De Kort 2017, Malpas 2017, Martens 2011, Muller 2012, Quill 2000-1, 2000-2, 2018-1, 2021-1, Rowell 2019, Saladin 2018, Schaffer 2016, Schwarz 2009, 2011, 2014 and 2016, Shacter 2016, Terman 2001, Webster 2016).

3.3 Pathophysiological and clinical consequences of stopping eating and drinking

The body obtains energy primarily from burning carbohydrates and fats. Glucose is the main fuel for most cells under normal conditions. During strict fasting, glucose is released from the liver during the first 24 hours by breakdown of glycogen (glycogenolysis) (Kerndt 1982, Owen 1983). However, this source is quickly depleted. Thereafter, the main sources of energy are:

- formation of glucose in the liver by conversion of amino acids, lactate and pyruvate (gluconeogenesis);
- formation of ketone bodies (acetone, acetoacetate and beta-hydroxybutyric acid) by breaking down free fatty acids; after some time, these become the main source of energy for the brain.

Over time, body proteins in the muscles and liver are also broken down to maintain blood glucose levels and thus the brain's energy supply. When the protein reserves of the muscles are used, increasing weakening occurs.

Strict fasting and little or no drinking are often well tolerated due to three factors:

- 1. Burning of fat produces ketone bodies, which leads to a decrease in appetite. In animal experiments, they also have an analgesic effect (Sullivan 1993).
- 2. After a few days, a state of well-being regularly develops under the influence of morphine-like substances (endorphins) that the body makes itself during strict fasting. This can also cause a decrease of pain.
- 3. Over time, with low fluid intake, increasing dehydration and progressive renal impairment occur, accompanied by drowsiness. This drowsiness is often experienced as pleasant. The feeling of hunger disappears after a few days, provided no carbohydrates (e.g. in soft drinks or in fruit) are ingested (Sullivan 1993).

Gordon et al studied 50 Palestinian prisoners in an Israeli prison after a hunger strike with a median duration of 38 days (range 28-44) (Gordon 2018). The prisoners had continued to drink, but it is not known how much fluid they ingested. The median age was 27 years (range 18-49). The most common complaints were chest pain (23%), abdominal pain (22%), flank pain (20%), weakness (20%) and dizziness (20%). Bradycardia was present in 62.5% and hypothermia in 32%. Laboratory tests showed (mostly mild) leukopenia in 62% of cases, (mostly mild) thrombopenia in 58%, anemia in 18% and a prolonged INR in 41%.

Bradycardia has also been described in starving in an experimental setting (Müller 2015) and in patients with anorexia nervosa (Galetta 2003). Hypothermia has also been described in patients with anorexia nervosa (Miller 2005).

When a patient with a life-threatening illness voluntarily stops eating and drinking, other factors also play a role. In the context of the disease, to a greater or lesser extent (depending on the nature of the disease and life expectancy), the so-called anorexia-cachexia syndrome (Guideline Anorexia and Weight Loss) may occur. This is characterized by the combination of anorexia (often combined with a feeling of early satiety), loss of muscle mass, weakness

and cachexia (extreme emaciation). Increased production of inflammatory mediators (cytokines) plays a role. Characteristically (unlike the situation in fasting), the loss of muscle mass and protein occurs at an early stage.

Only two studies have been published on the effect of cessation of fluid intake in healthy individuals (Phillips 1984, Terman 2006). The first study compared seven healthy elderly men (mean 70 years) with a group of seven healthy young men (20-30 years) who were given nothing to drink for 24 hours under laboratory conditions (Phillips 1984). It was found that the elderly, compared with the young, experienced much less thirst (despite a stronger increase in serum sodium) and dry mouth, and that the elderly were much less likely to replenish fluid deficiency after 24 hours. One explanation could be that there is a higher threshold for thirst sensations in the elderly. The mechanism of this is not known.

The second study described the findings of a 65-year-old healthy man who ate nothing for four days and drank only about 40 ml per day (Terman 2006). He experienced little hunger, but did experience thirst (graded as five on a scale of zero to 10), which was perceived as unpleasant. The thirst was manageable thanks to good oral care. He described a not unpleasant drowsiness after a few days, which was attributed to the ketone bodies produced.

No further literature has been found on the clinical consequences of voluntarily stopping drinking. It is often assumed that and increased serum sodium level leads to thirst. Studies in terminally ill patients (who would live another 2-35 days) who stopped drinking as part of the dying process show that their serum sodium level is usually normal (Vullo-Navich 1998). Although the patients with an elevated serum sodium level reported slightly more discomfort than those with a normal serum sodium level, the difference was small. There was no difference in patient-reported (dis)comfort in these terminally ill patients between patients who drank less than 500 ml per day and those who drank more. To what extent these data apply to patients with a longer life expectancy is not known.

Research and experience in terminally ill patients strongly suggest that good oral care (see also section 5.7.3) can largely eliminate the feeling of thirst and/or dry mouth (McCann 1994, Printz 1992, Vullo-Navich 1998, Van der Riet 2006, Guideline on dehydration and fluid administration.

After voluntarily stopping drinking, urine production eventually drops to a minimal level, stool volume decreases, respiratory mucus secretion decreases and eventually consciousness declines. Immediate causes of death include heart damage, arrhythmias due to hypokalemia, pneumonia and sepsis (Sullivan 1993).

3.4 Epidemiological data

In 1997, a publication appeared on the frequency of refraining from (artificial) administration of nutrition and fluids at the end of life in the Netherlands (Van der Heide 1997). In 8% of all deaths, death was found to follow a decision to discontinue fluid and nutrition. However, three-quarters of these cases involved partially or completely incompetent patients. Thus, the percentage found (8%) is not an accurate estimate of the number of deaths in which the patient **voluntarily** stopped eating and drinking.

Ganzini conducted a survey of 307 nurses in Oregon, USA (Ganzini 2003). 102 respondents reported that in the previous four years they had cared for a patient in a hospice who voluntarily stopped eating and drinking. See table 3.1 for specific patient characteristics.

In 2007, a frequency estimate of the annual number of deaths in the Netherlands due to voluntarily stopping eating and drinking was published for the first time (Chabot 2007; see also Chabot 2009). From a national sample, relatives of deceased patients (n=97) who had been involved in VSTED were traced. See table 3.1 for specific patient characteristics. Based on this sample, it was estimated that 2800 people per year (2.1% of all deaths) had died as a result of VSTED in the Netherlands in the period 1999-2003. In factor analysis, the reasons for the decision to stop eating and drinking fell into four groups:

- 1. somatic reasons (pain, shortness of breath, nausea/vomiting and general weakness/fatigue);
- 2. dependency (disability due to difficulty walking, blindness or deafness, inability to care for oneself, incontinence or fear of it, being a burden to others or fear of it, and/or loss of dignity or disempowerment);
- 3. demoralization (gloom, loneliness and/or perceived meaninglessness of life);
- 4. control of time and place of dying (the desire to control dying, the desire to die at home and/or being done with life).

Table 3.2 shows how often the above reasons played a role.

The Mortality Surveys of 2010 (Van der Heide 2012-1, Onwuteaka 2012) and 2015 (Hagens 2021) had a lower estimate of the number of people who died by voluntarily stopping eating and drinking, namely 600 per year (0.4% of all deaths in the Netherlands) in 2010, and 730 per year (0.5% of all deaths) in 2015.

However, the Chabot study and the Mortality Surveys are not easily comparable with each other because the information came from different types of respondents (in the case of Chabot relatives and in the case of Van der Heide doctors). The Mortality Surveys may lead to an underestimate of the frequency of occurrence of VSTED, partly because these surveys only included cases of stopping eating and drinking where a doctor was aware of. In contrast, the frequency estimate in the Chabot study may have been slightly overstated. This is because the relatives in that study sometimes incorrectly interpreted stopping eating and drinking as a deliberate intention to hasten the end of life. As a result, his frequency estimates may have been slightly too high. After correcting for this 4 the estimates in Chabot's study are still four times higher than those in the Mortality Studies (1.7% and 0.4% and 0.5%, respectively).

In the practice survey (part of the second evaluation of the Dutch Termination of Life on Request and Assisted Suicide Act, or euthanasia law for short), 45% of GPs, 57% of elderly care physicians and 42% of medical specialists had ever treated a patient who had voluntarily ended his life by stopping eating and drinking (Van der Heide 2012-2 and Bolt 2015-1). Bolt conducted a survey of a random sample of 1100 general practitioners (Bolt 2015-1). The response rate was 72%. Of the 708 respondents, 46% had ever had a patient under treatment who died as a result of VSTED; for 9%, it had been in the past year.

A more extensive questionnaire was completed by 285 GPs. Patients who had resumed eating and drinking, or who had advanced dementia, were excluded from the study. Patient details of the cases obtained (n=99) are shown in table 3.1. The estimated life expectancy was less than four weeks in 34% of cases, one to 12 months in 41% of cases and more than a year in 26% of cases. GP's rated the patient as fully competent in 90% of cases and partially competent in 7% of cases. In 50% of cases, the GP was not aware of the decision beforehand. 94% agreed with

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⁹ Personal communication Boudewijn Chabot, May 2013.

the patient's decision. They reported in 18% of cases that they themselves had given the patient the idea to stop eating and drinking.

The main reasons for VSTED from the studies by Chabot (2007) and Bolt (2015-1) are listed in Table 3.2.

Almost half of the deceased in the Chabot study had made a request for euthanasia that was not granted, according to respondents. According to the confidants, the main reasons given by the doctor for this were: the patient was not terminal or there was no fatal illness (21%), the patient did not have an illness (4%), the patient did not suffer unbearably or had prospect of improvement (26%), fear of legal consequences (17%) and the doctor's own philosophical views (20%). The 2010 (Van der Heide 2012-1) and 2015 (Hagens 2021) Mortality Surveys also show that almost half (43% and 45% respectively) of those who deliberately stopped eating and drinking had made a euthanasia request that was not granted. In Bolt's (2015-1) study, 19% had made a euthanasia request. This request had been refused in 14%; in 4%, euthanasia had not been performed for other reasons, including objections from the partner. Qualitative research shows that even patients who have not made an explicit request for euthanasia often prefer euthanasia to VSTED (Bolt 2023, unpublished).

The role of GPs and relatives in supporting a patient who stops eating and drinking is shown in table 3.3 (Bolt 2015-1). It shows that over 30% of GPs had no accompanying role in VSTED. In about 30% of cases, no relatives were involved in VSTED.

Bolt (2023) conducted a qualitative study through interviews with patients, relatives and healthcare providers involved in 29 cases of VSTED (Bolt 2023). 9 cases were included before stopping eating and drinking, 4 during stopping, 5 after the decision was reversed and 11 after death. In 24 of the 29 cases, patients had actually stopped eating and drinking; 19 of these patients died.

The patients in this study could be divided into three groups. The first group included patients who were elderly but still in relatively good health. They mostly had no death wish, but wanted to avoid losing control due to health deterioration by stopping eating and drinking. This group hardly involved others in decision-making, which sometimes made relatives feel overwhelmed. The second group involved elderly people with poor health whose world had become small and who had long had a death wish. They were largely dependent on their relatives and caregivers in the decision-making and preparation of stopping eating and drinking.

The third group included patients with chronic psychiatric conditions, who were often younger than the patients in the other two groups. Their death wish had been present for a long time and had sometimes led to suicide attempts, but could vary greatly over time. They experienced a lot of resistance from relatives or healthcare providers regarding their wish to start VSTED, which often meant they did not involve others in decision-making and preparation. Because they did not receive support, they often decided not to start VSTED after all or to do so in secret.

The prevalence of VSTED in Switzerland is estimated to be 0.5-0.7% (Stängle 2020-2 and 2021-3). Stängle et al conducted a survey of 1562 nursing homes in Switzerland (Stängle 2020-1). The response rate was 34%. VSTED was present in 1.7% of deaths in the nursing homes. No details were given about the patients.

Hoekstra et al. conducted a survey of 714 German general practitioners and palliative care physicians (Hoekstra 2015). The response rate was 29%. 62% of respondents had treated at least one patient in the past five years who had given up eating and drinking. 21% reported having seen more than five such patients during this period.

When asked, 149 respondents gave a description of the last patient they had had under treatment. See table 3.1 for specific patient characteristics.

Furthermore, there are several publications describing a total of 39 cases of patients who deliberately stopped eating and drinking and then actually died (Van Aarnhem 2011-1 and 2011-2, Ann 2016, Berry 2009, Brown 2016, Douglas 2016, Eddy 1994, Greenlaw 2016, Gruenewald 2018, Henry 2016, Jacobs 2003, Jansen 2002, Jose 2016, Koopmans 2004 and 2012, De Kort 2017, Malpas 2017, Martens 2011, Muller 2012, Quill 2000-1, 2000-2, 2018-1, 2021-1, Rowell 2019, Saladin 2018, Schaffer 2016, Schwarz 2009, 2011, 2014 and 2016, Shacter 2016, Terman 2001, Webster 2016). See table 3.1 for specific patient characteristics. Six patients were younger than 60 years of age. Two involved a second attempt (Ann 2016, Koopmans 2012) and one involved a third attempt (Jacobs 2003).

One case study (Fewing 2014) with commentary by Kirk (2014) and Meisel (2014) describes the dilemmas of an incompetent patient with dementia, in which the daughter insists on no longer offering food and drink. The outcome is not described. De Kort (2017) described two patients with impaired capacity, in which food and drink was stopped being offered.

Furthermore, two cases have been described of patients who started to stop eating and drinking, but later changed their minds and started eating again. The first case involved an 81-year-old woman with a subdural hematoma after a fall, COPD and depression which cleared up after treatment with an antidepressant (Kohlhase 2016). The second case involved a man with ALS who had started eating again when death did not come soon and he continued to be offered food in the hospital where he was admitted (Malpas 2014). Marks (2016) described the process of a patient preparing to discontinue food and fluids.

Table 3.1. Patient data studies VSTED

	Ganzini 2003	Chabot 2007	Van der Heide 2012-1 (Mortality- research 2010)	Bolt 2015-1	Hoekstra 2015	Hagens 2021 (Mortality survey 2015)	Case study 1994-2022
Respondents	Hospice nurses	Trust persons	Doctors	GPs	General practitioners and palliative care doctors	Doctors	Doctors, ethicists, relatives
Country	United States (Oregon)	Netherlands	Netherlands	Netherlands	Germany	Netherlands	Various countries
Frequency estimate VSTED per annum	-	2,800 (2.1% of all deaths)	600 (0.4% of all deaths)	-		730 (0.5% of all deaths)	
Number of patients	102	97	18	99	149	25	39
Woman	54%	60%	51%	-		76%	57%
Age	74 (mean)	80% > 60 years	96% > 65 years	70% > 80 years	65% > 70 years	82% > 80 years	Median 78 years Range 43-99
No partner	48%	70%	-			78%	<u> </u>
Main diagnoses	60% cancer, 16% cardiovascular disease and 23% nervous system diseases	40% fatal disease, 32% serious somatic or psychiatric disease, 28% defects but no disease	15% cancer, 14% cardiovascular diseases, 16% nervous system diseases and 54% other/unknown	27% cancer, 39% other serious physical illness, 12% early dementia, 7% psychiatric condition, 24% no serious physical or psychiatric condition*	58% cancer, 20% neurological disease	61% somatic disorder, 34% dementia, 63% accumulation of age-related complaints, 0% psychiatric disorders	23% cancer, 44% neurological disease, 10% other serious physical disease, 5% psychiatric disease, 18% no serious disease

^{*} multiple answers possible

Table 3.2. Reasons for patients to hasten end-of-life by stopping eating and drinking (Chabot 2007, Bolt 2015-1 and 2015-2)*

	Chabot 2007 n=97	Bolt 2015-1 and 2 n=99
Somatic	11-97	11-99
Weakness or fatigue	53%	60%
Pain	38%	18%
Breathlessness/fear of suffocation	10%	9%
Physical deterioration		51%
Other physical complaints		8%
Psychic		
Depressed	10%	16%
Fear		3%
Social		
Loneliness	11%	15%
Loss of a loved one		8%
Dependency		
Dependency	38%	32%
Not wanting to inconvenience others	22%	15%
Disability/immobility	23%	30%
No longer able to live independently		7%
Loss of dignity/self		
Loss of dignity	56%	29%
Cognitive decline or loss of		11%
communication		
Demoralisation		
Having no purpose in life	43%	38%
Suffering with no prospect of		41%
improvement		
Control of dying		
Completed life	59%	40%
Loss of direction	25%	27%

^{*} multiple answers possible

Table 3.3. Role of GPs and involvement of relatives in food and drink cessation (Bolt 2015-1)

Ac	companying role GP:*	Bolt 2015-1
-	In preparation	21%
-	In implementation (no palliative sedation)	27%
-	Palliative sedation until death	28%
-	None	38%
Ac	companying role of relatives:*	
-	In preparation	44%
-	In implementation	53%
-	None	28%
-	Do not know	3%

^{*} multiple answers possible

3.5 Course

In Ganzini's study, 85% of hospice patients died within 15 days (Ganzini 2003). On a scale of 0 to 10, nurses gave median scores of 2, 3 and 8 for pain, suffering and quality of dying, respectively. Over 90% of the nurses rated the dying process as 'good' and 8% as 'poor'. The latter group of patients had significantly higher scores for suffering and pain.

The time to death of the patients in Chabot's (2007) study is shown in table 3.4. Among the patients who died within 7 days (n=40), it was uncertain whether they died from the consequences of stopping eating and drinking or from the consequences of disease. Therefore, they were excluded (for scientific reasons) from the frequency estimation. Thus, the cohort described in Table 3.1 (n=97) consists only of patients who lived longer than 6 days after stopping eating and drinking. Regardless of the nature of the disease, the median duration to death was 13 days. That is, 50% died within 13 days.

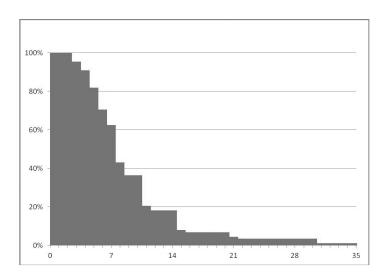
Table 3.4. How long does it take for death to occur? (Chabot 2007)

Duration from non-	In case of a fatal or	If there is no fatal or	Total
drinking to death	serious illness	serious disease	
< 7 days	40	0	40
7-9 days	19	5	24
10-12 days	17	4	21
13-15 days	12	10	22
16-18 days	3	1	4
19-30 days*	12	3	15
31-60 days*	6	2	8
> 60 days*	1	2	3
Total	110	27	137

^{*}These patients continued to drink more than 50 ml daily. The patient was then unlikely to die within 18 days.

The median time to death in Bolt's (2015-1) study was 7 days (see Figure 1). In 8%, the death process took longer than 2 weeks.

Figure 1. Survival curve, number of days between starting VSTED and death (Bolt 2015-1)



In the interview study (n=17 patients) by Eppel-Meichliner (2021), the median time to death was 14 days. Death lasted longer than 3 weeks in 5 cases (28, 35, 42, 63 and 66 days, respectively). In the interview study (n=20 patients) by Lowers (2021-2), the median time to death was 10 days (range 2-28).

Within the combined case studies, the median time to death was 11.5 days (range 6-24).

The process towards death was divided into 3 phases by Chabot (2007). The first phase (3-4 days) involved acute or gradual cessation of drinking. The middle phase was variable in length. During this period, diffuse pain or signs of delirium sometimes occurred. Analgesics and sedatives were the most commonly prescribed drugs during this period. During this phase, some people started drinking again. Thirst was not a prominent complaint and could in most cases be prevented or relieved by good oral care. The final phase lasted several days and was similar to the dying phase of a fatal disease.

10% of confidants spontaneously indicated that the death process had been painful or undignified; 40% spontaneously indicated that it had been good, calm, painless or dignified. The remaining relatives gave no spontaneous information about the course.

In Bolt's study (2015-1), a minority of GP's (36%) described that symptoms occurred in the last 3 days before death (11% did not know). The most commonly mentioned symptom was pain (14%). Palliative sedation was started in 28% of patients. In 80% of cases, according to the GP, the process went as the patient wished.

The collected cases also suggest a dying process that is generally acceptable and bearable for patients and relatives. However, the possibility of selection bias (only publication of cases that went relatively well) can certainly not be ruled out here.

In Bolt's retrospective series (2015-1), 5 out of 24 patients reconsidered their decision to stop eating and drinking. These included 3 patients younger than 50 years in whom psychological suffering was the reason for VSTED, 1 elderly patient with psychological suffering and 1 patient with dementia. In addition, there was 1 patient who committed suicide during VSTED by the ingestion of lethal drugs. In all these cases, lack of medical supervision played a role. There are 2 cases described in the literature where people started eating and drinking again (Kohlhase 2016, Malpas 2014).

In the retrospective study by Ganzini (2003), 16 out of 126 patients (13%) reversed their decision to stop eating and drinking. Other studies do not provide information on this.

3.6 Experiences of relatives and informal carers

In Bolt's interview study (2022), discussed earlier, the following points emerged regarding the experiences of relatives of patients who had deliberately stopped eating and drinking:

- Relatives sometimes had great difficulty in understanding the patient's decision, especially when the patient had not involved them much during the preparation. Nevertheless, relatives did want to help the patient because they saw that this was what the patient wanted.
- Some relatives described an ambiguity during the VSTED process: they wanted to help the patient to die because this was the patient's wish, but at the same time they did not want to see the patient suffer from thirst or other symptoms, and struggled to see their loved one deteriorate so quickly.
- In some cases, relatives felt very responsible for a smooth course of VSTED. Especially as the patient deteriorated, they would constantly sit next to the bedside to make sure no one would (accidentally) give drinks or the patient would suffer unnecessarily.
- Relatives often did not fully understand when the doctor would initiate palliative sedation, or why euthanasia was not performed. This could create unpleasant situations during the process, in which relatives would pressure the doctor to sedate the patient or proceed to euthanasia anyway.

- Relatives needed care and support from professional caregivers, but did not always receive it when VSTED happened in the home setting.
- When relatives could not fully understand the decision of the patient, they remained behind with questions and doubts afterwards. They could even be remain behind wondering whether they were right to cooperate.

Eppel-Meichlinger (2021) and Lowers (2021-2) conducted interview studies of 17 informal carers predominantly in Switzerland, and 24 informal carers in the United States, respectively, of patients who had voluntarily refrained from eating and drinking. The following themes emerged from the interviews:

- A predominant feeling among informal carers was that they had to act as the patient's advocate. That meant that they had to defend the choice to stop eating and drinking against the environment. They could only take on this role out of respect for the patient's autonomy and a conviction that this was the best choice for the patient and that there was no good alternative. However, this sometimes posed moral moral dilemmas.
- Partly related to the above, informal carers were often uncertain about the support they
 received from those around them and from healthcare professionals. They were often
 dissatisfied with professional care and sometimes felt abandoned.
- Informal carers often experienced increasing responsibility for the process as the patient became frail and lost focus.
- The informal carers often did not know what to expect and made different choices regarding their role: either as caregivers or as partners or children.

3.7 Views from healthcare professionals

Mattiasson (1994) conducted a survey of 157 nurses in 13 nursing homes in Sweden. 50% of the nurses personally felt that the patient's autonomy should be respected and that it was the patient's decision not to want to continue living. However, 80% of the nurses estimated that the ward would not let the patient die without intravenous administration of fluids.

In a survey of 307 nurses and 83 social workers, all working in a hospice in Oregon (USA), 85% felt that stopping eating and drinking was an acceptable option for patients with severe physical suffering and 76% for patients with severe psychological suffering (Harvath 2004). Only 5% found stopping eating and drinking immoral and 69% found stopping eating and drinking fundamentally different from PAS (physician-assisted suicide).

In the German study by Hoekstra (2015) discussed earlier, four patient vignettes were presented to respondents. Respondents had more difficulty stopping eating and drinking in the 85-year-old patient who had finished living and the patient with dementia, than in the patient with incurable cancer or with tetraplegia. About half of the respondents considered caring for. the elderly patient who had become tired of life to be assisted suicide. Nevertheless, in all four cases, the majority of the doctors interviewed believed that the patient was entitled to medical care In all four cases, they showed a great willingness to support the patient.

In Bolt's questionnaire survey, 81% of GPs said they thought it was conceivable to use palliative sedation in a patient who refrains from eating and drinking (Bolt 2015-1).

Stängle et al. reported on four surveys in Switzerland using a self-developed questionnaire (Stängle 2019-1) in:

- 1562 nurses in nursing homes (Stängle 2020-1). The response rate was 34%;
- 1616 home care nurses (Stängle 2021-3). The response rate was 24%.

- 1013 general practitioners (Stängle 2020-2). The response rate was 74%;
- a combined sample of 1562 nurses in nursing homes, 1616 nurses in home care and 1411 general practitioners (Stängle 2021-1). Response rates were 32%, 24% and 45% (overall 40%), respectively.

The main results are shown in table 3.5.

Table 3.5. Results of a survey in Switzerland among nurses in nursing homes and home care and among general practitioners.

	Stängle 2020-1	Stängle 2021-3	Stängle 2020-2	Stängle 2021-1
Target	Nursing	Nursing	GPs	Nursing
	experts in	experts in		experts in
	nursing homes	home care		nursing homes
	_			and home care
				and
				GPs
Number of respondents	535	395	751	1681
Experience of stopping eating and	48%	40%	43%	43%
drinking				
Death by stopping eating and drinking is:				
a natural death				
• passive euthanasia ¹⁰	65%	70%	59%	64%
• suicide	26%	17%	32%	27%
	4%	5%	5%	5%
Respects the decision	97%	97%	97%	97%
Believes that the patient has right to care	98%	98%	98%	98%
Finds it a dignified form of dying	71%	72%	75%	73%
Has moral doubts	13%	14%	22%	17%
Would recommend it to a patient	33%	48%	58%	48%
Would personally consider it an option	73%	76%	76%	75%

Stängle et al also conducted an interview study through 5 focus groups with a total of 47 caregivers (2 general practitioners, 14 nurses in nursing homes, 13 nurses in home care, 18 ethicists, politicians, volunteers and relatives) (Stängle 2021-2). Data from the focus groups were integrated with those from the national survey (Stängle 2021-1). In addition to the themes discussed earlier (see table 3.5), the following emerged:

- lack of knowledge among some healthcare providers;
- insufficient implementation of care for people who stop eating and drinking in Swiss institutions:
- lack of financial support for (time-consuming) care;
- discussion on stopping eating and drinking in incompetent patients;
- the importance of consensus within the treatment team and of interdisciplinary coordination and communication;
- giving patients space to go back on their decision to stop eating and drinking;
- the role of informal carers as the patient's advocate to defend her choice (as also described by the informal carers themselves);

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¹⁰ The term 'passive euthanasia' was used in the article, but is not common in the Netherlands today.

• the high burden on informal carers and the importance of good communication with and support for them.

In a survey in Japan of 440 palliative care experts and 131 hospice physicians, 32% said they had experience with patients who voluntarily stopped eating and drinking (Shinjo 2017). 15% of respondents thought stopping eating and drinking was acceptable, 36% thought it was not acceptable and 46% did not know.

4. Legal and ethical aspects

4.1 Summary

- VSTED is a right of anyone who is competent.
- The committee does not comment on whether VSTED is a (specific) form of suicide. The committee notes that VSTED differs from (other forms of) suicide in a number of morally and procedurally relevant points.
- Care for patients who choose VSTED is palliative care that should be offered to all. It is not assisted suicide.
- The death of a patient who dies due to VSTED is considered a natural death.
- VSTED is an option that can be brought up in end-of-life discussions and/or a death wish.
- The possibility of VSTED can be included in an advance directive as a (possible) wish for the future, but also if the patient has already made the decision for VSTED.
- The representative plays an important role in VSTED if the patient is incompetent at the time of decision-making or if the patient has become incompetent after stopping eating and drinking (e.g. due to delirium). The representative is expected to act in the interest and spirit of the patient.
- If a competent patient refuses nutrition and fluids, the healthcare providers involved refrain from artificially administering and offering nutrition and fluids.
- Healthcare providers may refrain from providing care to patients who opt for VSTED on grounds of conscientious objection. In that case, the healthcare provider should transfer the care to a colleague.

4.2 Introduction

This chapter describes the legal and ethical aspects of VSTED. It first discusses the basis of the right of the competent patient to choose VSTED. It then discusses VSTED in relation to suicide and support of VSTED as a form of palliative care. Next, VSTED is discussed in relation to advance care planning and giving information to the patient is described. This is followed by a discussion of the position of the patient's representative and the role of an advance directive. Differences between administering and offering nutrition and fluids, and conscientious objections among caregivers are then discussed.

4.3 Right to VSTED

People increasingly want to have control over their own end of life. To this end, people have a number of choices, one of which is VSTED.

VSTED is a right of anyone with the relevant capacity to exercise their will (Leenen 2020). It is a choice that people can and do make for themselves and for which they are not dependent on others. There is no requirement for VSTED to involve a healthcare provider or a relative, although this is urgently advised in order to best guide the process.

The basis for the right to choose VSTED is the patient's right to self-determination¹¹: the right of the competent patient to make her own decisions about her life and body. This right is enshrined, among others, in Article 10 of the Dutch Constitution (the right to respect for private life), Article 11 of the Dutch Constitution (the right to personal inviolability) and Article 8 of the European Convention on Human Rights (ECHR) (the right to respect for private life).

¹¹ The right to self-determination includes a right to defend oneself as well as the right to choose and the right to self-determination.

In the Pretty case, the European Court of Human Rights (ECtHR) mentioned for the first time that the right to self-determination is part of the right to respect for private life (Article 8 ECHR). ¹² Just as a refusal of treatment must be respected, so too must the decision of a competent person to stop eating and drinking be respected.

Administering fluids and nutrition against one's will (and thereby preventing VSTED) would essentially mean forcibly administering nutrition and/or fluids to people. Several basic and human rights oppose this, such as the right to personal inviolability enshrined in Article 11 of the Dutch Constitution.

4.4 VSTED in relation to suicide

Sometimes the question arises whether VSTED is a form of suicide. ¹³ There are different views on this in the literature. Some authors consider VSTED to be (a specific form of) suicide (Van den Brink 2015, Den Hartogh 2014 and 2023, Jox 2017, Lachman 2015, Menzel 2022, McGee 2017, Quill 2015-1, Schneider 2021), other authors see essential differences between VSTED and suicide (Pope 2011, Schmidhuber 2019) and yet other authors indicate that it depends on the circumstances (Jansen 2015, Moskop 2021, Schneider 2021). In surveys among Swiss GPs and nurses, 95-96% did not consider VSTED to be a form of suicide (see table 3.5, Stangle 2020-1, 2020-2, 2021-1 and 2021-3).

The aforementioned articles identify a number of aspects of VSTED, which would show that VSTED is either not suicide or differs from other forms of suicide in a number of relevant ways (Den Hartogh 2023):

- 'Letting' versus 'doing': in VSTED, an act (eating and drinking) is omitted, while in suicide, usually an active act (e.g. taking medication, inhalation of helium, hanging oneself) is performed (Moskop 2021, Pope 2011, Schmidhuber 2019). VSTED is seen as 'letting oneself die' (Schmidhuber 2019), while suicide can be seen as 'making oneself die'.
- VSTED can be understood as refusal of treatment (Moskop 2021, Pope 2011, Schmidhuber 2021, Schneider 2021).
- In VSTED, an internal, natural cause leads to death and a 'normal' dying process occurs (Jox 2017, Pope 2011). Thus, there is no external, unnatural factor.
- VSTED is not mutilating or violent (Jox 2019).
- VSTED is gradual. This means there is time for reflection and the patient can reconsider the decision during the process (Jox 2017, Schneider 2021). By ingesting small amounts of fluids or not, the patient can also partly control the pace of the process. This gradualness of the process also means that there is room to discuss any ambivalence towards the death wish with the patient.
- VSTED requires perseverance on the part of the patient (Jox 2017). This means that there can be no impulsive action (Schneider 2021) and voluntariness is almost guaranteed. Because the motivation for VSTED comes from the patient himself, there is almost no chance that VSTED will be performed under pressure from others.

The committee notes that there are different views in the literature on whether VSTED is a (specific form of) suicide. The committee makes no judgment in this matter. The committee does note that VSTED differs from (other forms of) suicide on morally and procedurally relevant points. The committee does not believe that an answer to this question is necessary either. Even if VSTED is seen as a specific form of suicide, the care to be provided is not

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 $^{^{\}rm 12}$ ECHR 29 April 2002, EJHL 2002, pp. 263-279 (Pretty v United Kingdom).

¹³ Parliamentary questions (Appendix) 2015-2016, no 466

assisted suicide. The committee sees it as palliative care, which should also be offered in other situations where people are suffering. This is explained in the next section.

4.5 Providing care during VSTED as a form of palliative care.

Competent patients have the right to make the choice to VSTED. In that respect, caring for people who stop eating and drinking is equivalent to caring for people who refuse treatment.

Healthcare providers providing patient care during VSTED respect the patient's autonomous decision and keep the patient comfortable. Care and support for a patient who has chosen VSTED are aimed at adequately and proportionately relieving the patient's suffering, not at causing or hastening the end of life. Therefore, caring people during VSTED is not assisted suicide.

Palliative care for people who have chosen VSTED may also imply that palliative sedation is an option under certain circumstances - as described in the Dutch Palliative Sedation Guideline. The argument that palliative sedation would not be allowed because people could end their suffering by restarting eating and drinking (and thus there is no refractory symptom) is not tenable in the committee's view. After all, starting to eat and drink again is considered not a reasonable alternative for the patient. Staying alive can be seen as an unacceptable 'side effect' of restarting eating and drinking. As a result, there may well be a refractory symptom and thus an indication for initiating palliative sedation. If the patient takes little or no fluids, the criterion of an estimated time to death of up to two weeks is also met (Palliative sedation guideline).

In the committee's view, there is no morally relevant distinction between palliative care for people who choose VSTED and palliative care in other situations, for example when refusing (other) treatment, such as antibiotics for pneumonia or discontinuing dialysis. Indeed, such a distinction would amount to depriving people who choose VSTED of adequate symptom relief.

In the committee's view, 'own fault' should not play a role in considering whether a person's symptoms may be remedied. All people who suffer are entitled to relief of that suffering, even if that suffering is the result of their own choice, such as the choice for VSTED.

A patient who opts for VSTED does not consent to the provision of life-extending care (including the provision of food and drink and the artificial administration of nutrition or fluids). She may, however, consent to the alleviation of symptoms.

Failure to provide palliative care at VSTED could legally be qualified as violating Article 255 of the Dutch Penal Code: abandoning of dependent persons in need of help. This article reads:

'Any person who intentionally puts or leaves in a helpless condition a person for whose maintenance, care or nursing he is responsible pursuant to the law or agreement shall be liable to a term of imprisonment not exceeding two years or a fine of the fourth category'.

The death of a patient who dies by deliberately stopping eating and drinking is considered a natural death and therefore does not need to be reported to the municipal coroner. As the immediate cause of death, the death certificate reports 'voluntarily stopping eating and drinking'. A death due to VSTED does not need be reported as a calamity.

4.6 Advance care planning

It is important that the healthcare provider and the patient have timely discussions about the end of life (see the Guideline Advance Care Planning) (KNMG 2021-3, Rietjens 2017). In those conversations, the patient's values, wishes and needs as well as the caregiver's responsibility, (im-)possibilities and limits regarding the end of life can be discussed. It is important to also involve the patient's representative (see section 4.9) in this conversation, provided this is allowed for by the patient.

This conversation is not always easy, both for patients and healthcare providers. Yet it is important to have this conversation in due time, as it allows mutual expectations to be discussed and misunderstandings to be avoided about what is appropriate and feasible care in the last phase of life and what the professional caregiver is and is not willing to do.

In doing so, the doctor can use, among other things, the KNMG guide Timely talking about the end of life (KNMG 2021-1). This guide contains discussion points that the doctor can use to explore the patient's questions and expectations. This guide was developed for doctors, but can also be used by other healthcare providers. A public version of this guide has also been developed (KNMG 2021-2).

It is common for people to want to find out about options for maintaining control over their own end of life and discuss this with a healthcare provider. Sometimes patients also have a current death wish. A healthcare provider should always talk to the patient in such situations. If a patient turns to a healthcare provider with a current death wish, it is important to ask about the background of this wish. Sometimes, behind a death wish is actually a request for help. The death wish may also stem from a mental illness or existential distress. In that case, it may be desirable to refer to the mental health services, a spiritual caregiver or another form of assistance (see also section 5.5.2).

4.7 Provision of information about VSTED by healthcare providers

If a competent patient wants to explore end-of-life options or has a well-considered death wish, the healthcare provider will start a conversation, exploring the request for help (KNMG 2021-1).

In those conversations, the healthcare provider discusses the patient's options, including the possibility of VSTED. Healthcare providers may also raise the possibility of VSTED themselves in that situation, obviously only when relevant to the patient in question. After all, it is the healthcare provider's responsibility to enable patients to make an informed decision about their own end of life. This also follows from the Dutch Medical Treatment Agreement Act (WGBO). In doing so, they respect the patient's autonomy. After all, autonomy means not only that healthcare providers respect patients' wishes as much as possible, but also that they give patients information that enables them to make a decision appropriate to their own life history. For a well-considered decision, it is important that patients are well informed about the different options that exist around the end of life and their advantages and disadvantages. Patients should be prevented from making decisions based on incorrect information and considerations.

Sometimes ignorance and misunderstandings exist in society about (the trajectory of) VSTED. For instance, people may think that VSTED always involves a lot of suffering. However, research and experience show that with proper preparation and guidance during the process, this is usually not the case (see Chapter 3, Empirical data).

Healthcare providers thus have a responsibility to inform competent patients with questions about end-of-life options or a well-considered death wish and their relatives about all options relevant to the patient, including (if applicable) VSTED. If VSTED is discussed, the caregiver provides information on, among other things, the preparation and course of the process of VSTED, its advantages and disadvantages and any expected problems, especially if the patient is young and/or in good physical condition (see also section 5.5.4). The healthcare provider also provides information about professional help and support that can be offered.

Providing information may also include referring to books, public brochures and reliable websites where information on VSTED can be found (see section 5.2). In this process of providing information, consultation and the possible active involvement of experts, for example in the field of palliative care or spiritual care, may be appropriate.

Informing patients about VSTED is not incitement to suicide. After all, these are competent patients who are looking for information about end-of-life options and want to discuss them. Educating patients gives them tools to make an informed, deliberate decision about their own end of life.

4.8 The role of an advance directive in VSTED

As part of advance care planning, the patient may draw up an advance directive. In it, the patient can state, for example, that she wants to refrain from (specific aspects of) treatment. This then concerns a so-called treatment refusal. An advance directive may also include (the possibility of) VSTED.

Regarding an advance directive with regard to VSTED, two situations can be distinguished:

- 1. The patient states stopping eating and drinking as a wish for the future. This may include, for example, people with a gradually progressing cognitive impairment (such as dementia), who are still able to exercise their will in this matter at the time of drafting the advance directive. The role of an earlier advance directive with regard to not offering or administering nutrition and fluids to people who have become incompetent in the course of the disease process is discussed in chapter 6.
- 2. The patient has already decided to VSTED and puts that decision in writing. Such an advance directive can specify, for example, how healthcare providers and relatives should act if the patient asks for fluids in a delirious (and incompetent) state. People starting VSTED are advised to prepare such a directive, for the situation that they become incompetent during the process of VSTED, and to discuss it with their representative. However, this is not a requirement (see section 5.6.4).

4.9 The position of the representative of the incompetent patient

If, in the course of the VSTED process, the patient becomes incompetent, she will have to be represented by another person (see section 5.6.4). The power to decide on the patient's treatment and care then passes to that representative.

The Dutch Medical Treatment Agreement Act (WGBO) prescribes that (in hierarchical order) the following are eligible as representatives: the patient's legal representative (curator or mentor); if this is missing, a personal representative; if this is missing, the spouse, partner or

partner in life; and if this is missing, the parent, child, sibling, grandchild or grandparent (Article 7:465 of the Dutch Civil Code/WGBO).

The patient's representative (in practice, usually the partner or a child) is expected to make decisions about the patient's care and treatment at the time the patient is no longer able to do so herself. In doing so, the representative is expected to act as a 'good representative' and to act in line with any advance directive, previous verbal expressions or a previous decision of the patient. A 'good care provider' is expected to monitor that the representative represents the patient's interests and to discuss this with the representative if doubts arise. A previously drafted advance directive about the desired care in a situation of delirium or in another situation can be helpful in this regard for both the representative and the caregiver.

In principle, the responsible caregiver must follow the decision of the representative, unless it would be contrary to the 'care of a good caregiver'. On this basis, it has the power to deviate from the representative's decision. This is the case, for example, when the responsible healthcare provider judges that the representative is not acting in the best interest or spirit of the patient. The responsible healthcare provider should discuss such a decision with other healthcare providers involved (multidisciplinary) and record it with reasons in the medical record. It is advisable to consult one or more (uninvolved) colleagues in advance of such a decision. The representative is informed of this.

4.10 Offering versus administering nutrition and fluids

If a competent patient opts for VSTED, the relatives and healthcare providers refrain from offering food and drink and administering nutrition and fluids during this process (see also section 2.4). The healthcare provider should respect the competent patient's wishes and not offer or administer food and fluids if the patient has indicated that he or she does not want them.

In general, not artificially administering fluids and nutrition will raise little discussion in this situation. The artificial administration of fluids and nutrition is seen as a medical (treatment) act, for which the patient (capable of giving consent) has the right to refuse under the Dutch WGBO.¹⁴

Not offering food and drink to patients who opt for VSTED may cause emotional problems for relatives and healthcare providers, as they may see food and drink as a form of basic care that they cannot and do not want to withhold from the patient. If necessary, healthcare providers can then invoke conscientious objection, provided it does not cause serious harm to the patient (see next section).

4.11 Conscientious objections

Healthcare providers may have conscientious objections to performing certain actions that are part of the professional standard.

Although caring for people who choose VSTED is a form of palliative care, some providers may perceive that they are providing poor care and/or facilitating the patient to hasten their own end of life. This may cause conscientious objections for a caregiver. In that case, the patient's choice conflicts with the caregiver's beliefs or personal values and norms.

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¹⁴ Article 7:450(1) BW.

Taking care of a patient generally means making sure someone eats and drinks enough. The same applies to caregivers. Eating and drinking is more than nutrition. Eating and drinking refers to life and also to living together. Stopping to offer food and drink because the patient chooses to hasten the end of life can make caregivers feel that they are providing poor care.

However, the healthcare provider has a duty to act as a 'good healthcare provider' even if she disagrees with her patient's choice that leads to health problems and/or hastening the end of life. A patient should not be deprived of appropriate care that comes with voluntarily stopping eating and drinking. When a healthcare provider has conscientious objections to providing this care, she should transfer (or have transferred) the patient's care to a fellow healthcare provider. The patient will be informed of this. A healthcare provider who invokes conscientious objections should provide care until the time of transfer to this colleague.

In this light, the KNMG Code of Conduct for Doctors (2022) is also important:

As a doctor, if you are unable to meet the needs of the patient due to a matter of conscience, you inform her or him of this and put her or him in contact with a colleague. Appealing to your conscience must not lead to any serious disadvantage to the patient. (Core Rule 11, KNMG 2022).

The Professional Code of Nursing and Caregivers says the following about conscientious objection (article 2.5):

As a nurse/carer, I have the right to refuse to cooperate with certain treatments on the basis of conscientious objections. Among other things, this means that I:

- refuse to cooperate in any action or acts that bring me into serious conflict with my philosophy of life or personal values and standards;
- make my conscientious objections known, whenever possible, in a timely manner;
- in case of conscientious objection, return the care to my supervisor or, if there is no supervisor, to one of my colleagues with motivation;
- as an independent worker, report my conscientious objections to the carer (or others involved) and provide care until it is taken over;
- do provide care that is not directly related to the act or procedure against which I have conscientious objections, unless that care is also taken over by a colleague.

Part 2 Caring for people who voluntarily stop eating and drinking to hasten the end of life

5. Decision-making, guidance and care

5.1 Summary

General

- Explore the feelings and considerations of relatives and involve them in decision-making, preparation and implementation.
- Check at all stages if there is any overburdening of relatives and if support is needed for this.
- Also pay attention to the emotions and burden of the caregivers involved.
- If necessary, consult the palliative care guidelines and other relevant guidelines.
- If necessary, seek advice, e.g. from a palliative care consultation team or a spiritual caregiver.

Decision-making

- Check what factors underlie the decision for VSTED; consider interventions (if possible and desired by the patient) and, if necessary, consultation, e.g. from a palliative care team, an elderly care physician, a spiritual caregiver, a psychologist or a psychiatrist.
- Inform the patient as well and objectively as possible about the expected course and the pros and cons of VSTED; also discuss expected problems with the patient; indicate where good and reliable information can be found.
- Discourage stopping eating and drinking without proper preparation and support from relatives (if available) and/or professional caregivers.

Preparation

- Inform patient and relatives;
 - how to stop eating and drinking;
 - that hunger usually disappears within a few days and thirst can often be relieved by good oral care;
 - that there is always room and opportunity during the process to reconsider the decision to stop eating and drinking;
 - that most people die within 1-2 weeks if they consistently drink little or nothing, but that it may take longer if some drinking continues or in young patients (<60 years) if there is no life-threatening illness;
 - that good oral care, sleep medication and sometimes painkillers and sedatives are essential;
 - that there is often highly variable but gradually increasing drowsiness and that this may include confusion (delirium);
 - that palliative sedation can be used in some situations, but only in the course of the process, if there is unbearable suffering due to one or more refractory symptoms at that time.
- If necessary, arrange for adjustment of the bed (preferably high-low bed), an antidecubitus mattress, resources for oral care, a bedpan, urinal or incontinence material and possibly resources for an enema; if necessary, consult with a cardiologist about turning off an ICD.
- Pay attention to:
 - material and immaterial issues that still need to be arranged and finished respectively;
 - saying goodbye;

- the wish for rituals before and/or after the death, the course of action after death (physical care, clothes, burial) and the arrangement and design of the funeral/cremation.
- Adjust medication:
 - Continue only strictly necessary medication.
 - Anticipate problems that may come up and prescribe the necessary medication.
 - Prescribe medication that can be given transmucosally (sublingually, buccally, oromucosally or intranasally), transdermally, s.c., i.v. or rectally.
- Check whether care can take place at home; if not, consider transfer to a hospice or palliative unit (provided these institutions are willing to provide the care).
- Deploy the required and desired care (nurses family support, domestic support, volunteers and/or spiritual care); verify that all caregivers involved are willing to provide care for patients who voluntarily stop eating and drinking; inform the patient and relatives about who is present, when they are present and how they can be contacted; ensure proper coordination of care and documentation in a file present with the patient.
- Advise preparation of an advance directive, in which the patient documents:
 - that she voluntarily stops eating and drinking to hasten the end of life;
 - that she does not want to be admitted to a hospital;
 - that she does not consent to the offering of food and drink and the artificial administration of nutrition and fluids;
 - that she refrains from life-extending treatments (including resuscitation);
 - how to act when she asks for fluids in a delirious state.
- Make sure a representative is appointed.

Executive phase: initial phase

- In consultation with the patient, decrease eating (usually immediately) and drinking (immediately or gradually, over the course of several days).
- Start body, skin and oral care. If possible and desired, involve the relatives.
- Engage with the patient if she indicates she cannot continue or wants to go back on her decision to refrain from eating and drinking.

Executive phase: middle phase

- Pay close attention to oral care.
- If the patient can no longer use the toilet chair or toilet, provide a bedpan, urinal, incontinence material, mat, condom catheter or indwelling catheter.
- Check for a full rectum and give a bisacodyl supp or a (mini)enema if necessary.
- If necessary, treat symptoms such as pain, dyspnoea, nausea, vomiting, agitation, confusion and delirium.
- Start continuous palliative sedation only if there is unbearable suffering due to one or more refractory symptoms and if the patient has demonstrated the ability to actually stop drinking; otherwise, the condition of a life expectancy < 2 weeks is not met. When in doubt, short-term ('time-out') or intermittent sedation may be chosen.

Executive phase: dying phase

- Mark the dying phase and inform the patient (if still conscious), relatives and relevant caregivers.
- Treat complaints and problems (e.g. terminal delirium, death rattle) in accordance with palliative care guidelines.

- After death, issue a certificate of natural death, entering 'stopping eating and drinking' as the immediate cause of death.
- Offer an appointment for an after-care discussion with relatives. Evaluate the entire process with the caregivers involved, offering space for emotions.

5.2 Introduction

This chapter discusses decision-making, guidance and direct care of the patient who voluntarily stops eating and drinking and her relatives. Depending on where the patient stays (usually at home, in the nursing home or hospice) and the circumstances, the following healthcare providers may be involved in decision-making, counselling and care:

- doctors, in practice mainly general practitioners, elderly care physicians, and hospice doctors;
- physician assistants;
- nursing specialists;
- nurses;
- spiritual caregivers;
- volunteers.

In addition to the above persons, family members and/or other trusted persons (collectively referred to as relatives for short) play a crucial role in care and guidance. The following first discusses the role of relatives. The rest of the chapter deals with the professional aspects of decision-making, guidance and care. In that respect, organization and coordination of care are essential. Professional carers, volunteers and relatives share responsibilities. Professionals can be expected to take the lead in this.

By guiding and caring for the patient, healthcare providers and relatives alleviate the suffering and possible complications that may arise as a result of stopping eating and drinking. Continuity of care can be achieved through good cooperation, with mutual coordination between healthcare providers, and between healthcare providers on the one hand and the patient and relatives on the other. If necessary, it is wise for the responsible caregiver to call on, collaborate with and/or seek advice from experts, such as elderly care physicians, physician assistants, nursing specialists, nurses, spiritual caregivers and/or palliative care consultation teams. When a caregiver is in doubt about her own expertise, it is always the professional norm to consult the appropriate expert in a timely manner. This expertise is accessible and available to all caregivers.

Lack of cooperation and coordination can have major consequences for patients and their relatives as well as healthcare providers. It is therefore very important that good agreements are made between all involved. Healthcare providers record relevant data relating to the patient in the medical file. The attending physician ensures, especially for evening, night and weekend hours, an adequate transfer to the substitute physician and other care providers involved. The healthcare providers involved should be easily accessible and available to the patient. Physician assistants, nursing specialists and nurses and also ensure an adequate handover.

A number of recent reviews focus on the decision-making, preparation and implementation of VSTED (Ivanovic 2014, Lowers 2021-1, Gruenewald 2018 and 2020, Quill 2018-1 and 2018-2, Wax 2018). To our knowledge, there are no other manuals or guidelines in this area nationally or internationally (Mayers 2019). Gruenewald (2018 and 2020) provides extensive practical information on VSTED in nursing homes.

This guide is primarily written for doctors, physician assistants, nurse specialists and nurses, but can also be read by other healthcare professionals, volunteers, patients and relatives. However, the wording and terminology are tailored to doctors, physician assistants nurse specialists and nurses. Patients and relatives can find in the book 'Uitweg' the information to best guide and care for the patient during the process of voluntarily stopping eating and drinking (Chabot 2022). Furthermore, the NVVE's Dutch brochure 'Voluntarily stop eating and drinking' (2022) can also be used, as well as the Dutch podcast with an interview with Eva Bolt.

5.3 The role of relatives

Research shows that people who want to opt for VSTED often discuss this wish with one or more confidents or relatives before approaching a doctor about it (Bolt 2023, Chabot 2007 and 2009, Eppel-Meichlinger 2021, Lowers 2021-2). These relatives¹⁵ are emotionally attached to this person. As a result, they have a better view than anyone else of what still binds her to life or what drives her to want to die.

Conversations between people with a death wish and their relatives far from always culminate in a request for dying assistance to the healthcare provider. If they do, it may take the form of a euthanasia request or a request for palliative support during stopping with eating and drinking. Here, the role of relatives as intermediaries between patient and caregiver is essential. They can provide insight into remaining options or limitations. Moreover, people considering VSTED may reconsider taking this route if their relatives are unwilling or unable to provide care and support. Resistance by relatives to the patient's wish to die can play an important role in decision-making, with the doctor sometimes playing a mediating role. This resistance may also affect the implementation of the VSTED process.

When people choose VSTED, relatives have a crucial role from day to day. They often take turns and are often involved in (oral) care. They are also the eyes and ears of professional caregivers in spotting symptoms and complaints, and in assessing whether these are sufficiently under control. It is important here to cooperate and coordinate well with relatives as an involved professional caregiver.

5.4 Care and guidance by phase

Care and guidance are described by phase (Chabot 2007, see also section 3.5):

- 1. the decision-making phase;
- 2. the preparatory phase;
- 3. the executive phase:
 - the initial phase (usually a few days), during which eating and drinking are acutely or gradually stopped:
 - the middle phase (highly variable in length, depending partly on the physical condition at the start and on the speed and extent to which eating and drinking are gradually diminished);
 - the dying phase (the last days before death and shortly after death).

In practice, these phases cannot be strictly separated and often blend together gradually. Some preparations are not yet completed or even started when the patient already stops eating and

¹⁵ Often one of the relatives, as the 'linchpin', is more intensely involved in decision-making than the others. Nevertheless, 'relative' is referred to here in plural, because the wider circle is a sounding board for this linchpin and is additionally involved in the care, after a decision has been made.

drinking. Sometimes the healthcare provider is not involved until the patient has already stopped. In that case, all aspects discussed in section 5.6 under the preparatory phase will only come up during the executive phase.

5.5 Decision-making

5.5.1 Determination of competence

What is important is that the patient is capable of making a well-considered decision with regard to VSTED. The decision to stop eating and drinking is a decision that places high demands on the patient's decision-making skills and for which the determination of competence may be indicated (see also the guide Decisional capacity and competence of the Long-term Care Quality Impulse Foundation, SKILZ). For the determination of (in)competence, see the KNMG step-by-step plan (KNMG 2004). SKILZ's guide also provides a step-by-step plan. See also chapter 2.

The patient does not have to prove her competence. It is the healthcare provider who must make it plausible that the patient is no longer considered capable of a reasonable appreciation of her interests in the matter (see section 2.3). When in doubt about the patient's competence, it is advisable (but not mandatory) to consult a colleague, elderly care physician or a psychiatrist. For stopping the offering of food and drink to incompetent patients in this matter, see chapter 6.

5.5.2 Exploration of factors underlying the decision to VSTED

If a patient indicates a desire to stop eating and drinking, the factors underlying the decision to VSTED are explored and whether interventions or consultation (e.g. from a palliative care team, psychologist, psychiatrist or spiritual caregiver) are possible and desirable in this regard.

These factors may include (Van Aarnhem 2011-1 and 2011-2, Gruenewald 2018, Lowers 2021-1, Quill 2018-1, Wax 2018):

- a. physical or psychological symptoms, which are not under control;
- b. depression, eating disorder or other mental disorders;
- c. existential issues;
- d. a rejected euthanasia request;
- e. outside pressure.

Re a) If the death wish stems from physical or psychological symptoms (e.g. pain, dyspnoea or anxiety) that cannot be controlled, the healthcare provider explores whether treatment of these is possible and whether this treatment is desired by the patient.

Re b) The death wish may also be related to a psychiatric condition that the patient (may) have, such as a depression or an eating disorder. In such a case, the question may arise for the healthcare provider as to what extent the decision to stop eating and drinking is taken under the influence of that (suspected) mental disorder. First, this often requires further diagnostics by a specialized healthcare provider. In that case, the healthcare provider may refer the patient the mental health services for (emergency) care. If the patient is already known to have a mental disorder and is already receiving treatment for it, the healthcare provider consults with the treating physician to form a picture of the influence of that illness on the death wish. In principle, this requires the patient's consent, but in emergency situations consultations can be held without the patient's consent.

The fact that the patient has a mental disorder does not necessarily mean that the patient cannot decide to stop eating and drinking, even if the death wish is (partly) motivated by the mental disorder. Indeed, the patient may be competent with regard to her death wish and has the right to choose to stop eating and drinking. SKILZ's Decisional capacity and competence guide mentions the criterion being free of compelling influences from within in this regard.

In practice, the question arises whether, if the patient does not want diagnosis and treatment, the healthcare provider can oblige her to do so. These questions cannot be answered in advance. This will depend on the circumstances of the case. Given that VSTED involves acute danger to life, involuntary care may be considered as a last resort in exceptional cases of mental illness. The Dutch Compulsory Mental Health Care Act (Wvggz) then applies.

Re c) As discussed in Chapter 3 (Empirical data), existential factors often play a role in the decision to forgo eating and drinking. In the interview, the caregiver explores whether this is the case and whether consultation with a spiritual caregiver is appropriate and desired.

Re d) A person's decision to stop eating and drinking may be related to a rejected euthanasia request. If this decision is made out of anger about that rejection, then the struggle over it may shift to whether or not to eat and drink. This disappointment and sometimes anger can make preparation and counselling a difficult process for the patient and professional caregiver (Van Aarnhem 2011-1 and 2011-2). Sometimes this leads to a disturbed relationship between the professional caregiver and patient. It is therefore important to keep making attempts to restore the relationship and (continue to) properly inform the patient about the reason why the euthanasia request cannot be granted.

Obviously, however, an unmet euthanasia request does not prevent a trajectory with VSTED. The committee assumes the situation in which the euthanasia request cannot be granted because the due care criteria for euthanasia have not been met (see KNMG position paper Decisions around the end of life (2021-3). If the situation has changed and the due care criteria are possibly met, the request for euthanasia may be reconsidered.

Some people prefer VSTED to euthanasia because they do not want to depend on a doctor to fulfil their death wish, do not want to burden another person with performing euthanasia or have fundamental or emotional objections to euthanasia.

Re e) In the conversation with the patient, the healthcare provider explores whether the decision to refrain from eating and drinking is an autonomous decision by the patient and whether there is no external pressure. If there does seem to be external pressure, the healthcare provider will enter into a discussion with the patient about her motives, and possibly also with relatives. The starting point is always the patient's wishes. If necessary, assistance can be called in.

5.5.3 Role of relatives and professional caregivers in decision-making

Often, the patient himself will already have talked to relatives about the death wish and the intention to stop eating and drinking. Sometimes, however, the patient needs to be encouraged to do so. The process of VSTED requires good care. The patient should therefore be discouraged from stopping eating and drinking without proper preparation and support from caregivers and relatives (Chabot 2013, Quill 2012, Schwarz 2007). This is because the patient will become weakened and needy and the symptoms that arise as a result of not eating and

drinking are unlikely to be adequately alleviated without help. In addition to support, care and nursing by relatives, volunteers and/or nurses, medical support is strongly recommended to achieve the patient's goal in the best possible way.

5.5.4 Informing the patient

The healthcare provider informs the patient as well and objectively as possible about the expected course and the pros and cons of VSTED. The healthcare provider also alerts the patient to expected symptoms and problems, especially if the patient is young.

The (potential) advantages of VSTED are that:

- the patient is largely in control of the decision and implementation, and thus not dependent on others;
- in the case of a death wish, this is a way to death if euthanasia is not possible or desired by the patient;
- voluntarily and consistently stopping eating and drinking is sure to lead to death if eating and drinking are consequently stopped;
- the patient can still reconsider her decision during the process of VSTED;
- the gradual and sometimes lengthy course of the VSTED process makes it possible to say goodbye properly.

The (potential) drawbacks of VSTED are that:

- it can take 1-3 weeks and sometimes longer for the patient to die;
- symptoms occur during this period, which are sometimes difficult to alleviate;
- the relatively long duration until death can be stressful for the patient and/or relatives.

In the earlier (2014) version of this guide, VSTED was discouraged for people under 60 years of age. The reason was that there were no case histories of people under 60 years of age ending their lives due to VSTED. However, several cases have since been described that show that people younger than 60 can also end their life by stopping eating and drinking (see Chapter 3, Table 3.1). The committee therefore no longer uses an age limit to advise against stopping eating and drinking.

In people who are younger than 60 years of age and who do not have a life-threatening illness, however, the process of stopping eating and drinking can be longer and more difficult. This is partly due to the (often better) physical condition of younger people. Moreover, at younger ages the ability to concentrate urine is greater, so dehydration occurs later. Also, younger people have a stronger thirst sensation, making it harder to maintain not drinking.

In elderly people, VSTED need not be advised against on the basis that there is no life-threatening illness or that the person is still in good condition.

Informing may also include pointing out the importance of good and reliable information, where it is available (see section 5.2, last paragraph) and sharing experiences the healthcare provider has had with other patients. In this conversation, the patient can also be made aware of other options for a humane self-chosen end of life. Discussion of these is beyond the scope of this guide.

5.6 Preparatory phase

The preparatory phase covers:

- information, preparation and support of patient and relatives;
- adjustment of medication;
- organization and coordination of care;
- preparing an advance directive and appointing a representative.

Obviously, not all the issues mentioned above need to be addressed in one conversation. Some are not applicable in specific situations, others are not (yet) easy to discuss and/or are better discussed at a later stage.

5.6.1 Information, preparation and support of patient and relatives

The preparatory conversation is primarily conducted by the doctor, physician assistant or nursing specialist, preferably together with a nurse.

In the preparatory conversation, it is discussed that:

- eating can be stopped quickly and hunger usually disappears within a few days;
- with regard to drinking, one can choose to gradually diminish or stop abruptly (see section 5.7.1);
- thirst and dry mouth can usually be relieved by good oral care;
- there is always room and opportunity during the process to reconsider the decision to forgo eating and drinking;
- most people die within 1-2 weeks from the time they stop drinking or drink very little, but the length of this period is affected by the physical condition at the time of stopping eating and drinking, and that it can take weeks or even several months until death if people do continue to take fluids;
- the process of VSTED is expected to be more difficult and longer in young patients (<60 years), in whom there is no life-threatening disease;
- good oral care, sleep medication and sometimes painkillers and sedatives are essential;
- there is often a highly variable but gradually increasing drowsiness and this may also include confusion (delirium);
- discomfort and suffering cannot always be avoided even with maximum support;
- palliative sedation can be used in some situations, but only if there is a refractory symptom in the course of the process.

The preparatory conversation gauges the extent to which the relatives support the patient's decision. Those close to the patient may sometimes find it difficult to accept the patient's decision. There may also be feelings of guilt, feelings of having fallen short, lack of understanding or anger about the patient's decision. In such situations, it is good to discuss this. Good support and guidance of the patient by relatives are essential to make the process as smooth as possible. Ambivalence or resistance from relatives makes the process much more difficult for all concerned.

The conversation will also check the following:

- for an admitted patient: whether the patient wants to die at home or in a hospice, nursing home or hospital and whether the opportunity to do so exists;
- if the patient is at home: whether relatives are able to provide the necessary care at home (with support from home care and/or volunteers, if desired). Transfer to a hospice or palliative unit may be considered. However, it should be checked whether the hospice or palliative unit in question is willing to provide care for a patient who deliberately stops eating and drinking to hasten the end of life.

As discussed in section 5.5.2, a denied euthanasia request can complicate the process, and it is essential to engage in a dialogue about it, both with the patient and with relatives. A reconsideration of the euthanasia request is in order if the situation has changed and in the meantime the due care criteria can now possibly be met.

It is important to discuss how relatives and caregivers can deal with requests from the patient to drink anyway. In such situations, it is first asked whether the patient is sure she wants to drink. If the answer is affirmative and if the patient is capable of giving her consent to the request, the request is always granted. After all, the patient must have the opportunity to go back on her decision. A special situation arises if the patient requests fluids in a delirious state (see section 5.8.5).

The following is also discussed:

- adjustment of the bed (preferably high-low bed) and the presence of an anti-decubitus mattress:
- resources necessary for oral care;
- the presence of a bedpan, urinal or incontinence material and the need/want for a bladder catheter;
- giving an enema if necessary;
- if applicable: consult with a cardiologist about turning off an ICD. A pacemaker does not need to be turned off.

The conversation may also address:

- financial/legal arrangements still to be made (e.g. will, authorization for payments, etc.);
- preparing an advance directive and appointing a representative (see 5.6.4);
- other issues (material and immaterial) that still need to be arranged or finished;
- saying goodbye;
- desire for rituals before and/or after death;
- course of action after death (physical care, clothing, burial);
- arranging and shaping the funeral/cremation.

To support patient and relatives, the following may be used:

- at home:
 - home care nurses (if desired and not yet involved); check whether these would be willing to care for a patient who voluntarily stops eating and drinking;
 - domestic support;
 - palliative terminal care volunteers; these volunteers are trained and educated to watch over, babysit, help with practical care, inform patients and provide emotional support, take on occasional care tasks and identify and report changes in the care situation.
- spiritual caregiver; she can play an important role in, for example, questions of meaning, unfinished business, guidance and support for relatives, wishes for rituals around death and discussing and shaping the cremation or burial. See also the Guideline on Meaning and spirituality in the palliative phase.

5.6.2 Adjustment of medication

• Medication for which there is no indication (anymore) (e.g. statins, diuretics, antihypertensives, anticoagulants, antidiabetics or bisphosphonates) is discontinued. Only

- medication targeting existing symptoms, e.g. pain, shortness of breath or nausea, is continued.
- Medication, where withdrawal symptoms may occur on discontinuation (opioids and benzodiazepines) are continued, especially if they have been given for a long time and/or in high doses.
- Corticosteroids (prednisone or dexamethasone) are preferably discontinued given their appetite-promoting effects, unless this medication is necessary to control neurological symptoms or other symptoms. When the patient has used the corticosteroids for a long time (> 4 weeks) or in high doses (dexamethasone > 4mg/day, prednisolone > 30 mg/day), they are tapered off and discontinued in a few days to a week. These drugs can be administered subcutaneously during the phase-out period.
- In principle, antiepileptic drugs are discontinued unless it is estimated that there is a high risk of seizures. In that case, valproic acid rectally or levetiracetam s.c. can be given as maintenance. In case of seizures, midazolam is given intranasally or subcutaneously, if possible.
- The medication, especially during the course of VSTED, is no longer administered orally. Alternative routes of administration are:
 - rectally. A number of drugs can be administered as suppositories. Sometimes oral forms of administration can also be given rectally, e.g. temazepam. Diazepam can also be given rectally. In some cases, different doses are given rectally than orally. An objection to rectal administration is that it can be burdensome for severely debilitated patients to put them in the position required for administration, and the drugs sometimes come out before they are resorbed in the rectum. The rectal route of administration is therefore not preferred;
 - through the mucous membranes of the oral and nasal cavities (transmucosal):
 - sublingual (under the tongue);
 - buccal (via the cheek mucosa);
 - oromucosal (via the mucosa of the gums);
 - intranasal (via the nasal mucosa).
 - transdermal (as a patch);
 - subcutaneously (under the skin), as intermittent injections or via continuous subcutaneous infusion using a pump. This involves the use of a subcutaneous indwelling needle. The prerequisite for intermittent administration is, of course, that someone is available to give the subcutaneous injection at the agreed time(s);
 - intramuscularly (into the muscle). However, intramuscular administration of medication is rarely, if ever, necessary. An intramuscular injection can be painful. Virtually all drugs administered intramuscularly can also be administered subcutaneously. The subcutaneous route of administration is strongly preferred;
 - intravenously (via the bloodstream). This is only possible if there is a central line (e.g. a PICC line, subclavian catheter, fully implantable delivery system or Hickman catheter). In other cases, subcutaneous administration is therefore strongly preferred.
- Furthermore, the following medication is prescribed:
 - medication for sleep;
 - analgesics for acute pain;
 - if deemed necessary: other medication for symptoms that might occur in the patient in the short term (e.g. shortness of breath, delirium, seizures or anxiety).

All these medications are taken on indication. The medication can be given under the patient's own management after proper explanation (provided there are no cognitive problems).

It is clearly agreed and documented which medication is given, when it is given, for which indication, in which dosage, by which route of administration and who administers the medication. See table 5.1 for an overview of some commonly used drugs with alternative routes of administration.

Table 5.1 Commonly used drugs and non-oral routes of administration

Indication		Resources	Non-oral route of administration
Pain Maintenance treatment		Paracetamol	Rectal
		Slow release morphine or	Rectal (resorption uncertain)
		slow release oxycodone	-
		Immediate release morphine	Intermittently or continuously s.c.
		or oxycodone	or i.v.
		Fentanyl	Transdermal (patch)
		Buprenorphine	Transdermal (patch)
	Breakthrough	Immediate release morphine	Rectal, s.c. or i.v.
	medication	Immediate release	S.c. or i.v.
		oxycodone	
		Fentanyl	Sublingual
			Oromucosal
			Buccal
			Intranasal
		Buprenorphine	Sublingual
Nausea	and vomiting	Metoclopramide	Rectal, s.c. or i.v.
		Haloperidol	Buccal, s.c. or i.v.
		Levomepromazine	Buccal, s.c. or i.v.
Obstipa	tion	Bisacodyl	Rectal
		Sodium lauryl sulfoacetate	Rectal
		Phosphate enema	Rectal
		Methylnaltrexone	S.c.
Deliriun	n	Haloperidol	Buccal, s.c. or i.v.
Sleep pr	oblems, anxiety and	Temazepam	Rectal
sedation		Midazolam	Intranasal, buccal, s.c. or i.v.
		Lorazepam	Sublingual, s.c. or i.v.
		Diazepam	Rectal or i.v.
		Clonazepam	Sublingual, s.c. or i.v.
		Levomepromazine	Buccal, s.c. or i.v.

5.6.3 Organization and coordination of care

Clear agreements are made (and recorded in the medical file) on:

- the willingness and involvement of caregivers and relatives, and their mutual division of tasks and responsibilities;
- how often and at what times caregivers, volunteers and relatives will be present. How
 these arrangements are made depends on a) the patient's wishes, b) her physical condition
 (which will increasingly deteriorate as the process progresses) and c) the presence and
 willingness/ability of relatives to provide care. In most cases, someone (a relative,
 volunteer and/or professional caregiver) will (have to) be present continuously after a few
 days;
- accessibility of healthcare providers within and outside office hours.

Wherever the patient stays, mutual communication and coordination are essential. This implies:

• proper handover within all disciplines involved, ensuring continuity of care even outside office hours;

- recording who the first contact person is;
- interdisciplinary consultations and consultation with the patient and relatives;
- preparation of a care plan;
- proper reporting of daily particulars and agreements made, preferably in a central file (in the home situation, the home care file) or in a care pathway.

5.6.4 Advance directive and appointment of representative

It is recommended (but not required) that the patient put in writing:

- that she voluntarily stops eating and drinking;
- that she does not want to be admitted to a hospital;
- that she does not consent to the offering of food and drink and the artificial administration of nutrition and fluids;
- that she refrains from life-extending treatments (including resuscitation);
- how to act when she asks for food and drink in a delirious state;
- who the representative is if the patient becomes incompetent.

An advance directive may be drafted and written down by another person, but must be signed by the patient herself. Optionally, the text may be recorded by the patient in an audio-visual recording.

5.7 Executive phase: initial phase

At the beginning of the executive phase, the patient more or less gradually discontinues eating and drinking, usually over the course of several days, but sometimes faster or slower. General physical care (depending on the patient's physical condition) and oral care are started. Physical care and oral care are continued in the middle and dying phases. At all stages of the process, good support of the relatives and good care of the caregivers are very important.

5.7.1 Withdrawal of food and drink

Eating can be stopped quickly or even immediately in many cases, especially if appetite is already greatly reduced. The feeling of hunger (if present) generally disappears within a few days. The prerequisite for this is that the patient does not ingest carbohydrates (e.g. in fruit (juices) or soft drinks).

There is no general advice for when to stop drinking. Some people want to stop drinking abruptly overnight. Others prefer to reduce drinking over the course of a few days to the minimum amount (less than 50 ml/day) needed for oral care. Still others continue to drink more than 50 ml of water every day. In that case the process may well take (much) longer than 2 weeks.

During this period, the patient can experience what it is like to have little or nothing left to drink and whether this can be made bearable with good oral care. This may also reveal how strong her death wish is. Sometimes the patient goes back on her decision to stop eating and drinking. How often this happens is not known. If the patient indicates she is unsure about her decision, it is important to discuss this and highlight the different aspects of her initial decision by discussing the pros and cons. Relatives are included in this conversation, unless the patient explicitly does not want this. Ultimately, it is up to the patient to decide whether to stick with her decision to stop eating and drinking or to go back on it.

5.7.2 General physical care and skin care

Whether, and to what extent, physical care is necessary depends on the patient's physical condition. Sometimes care is necessary from the start, sometimes only during the course of the process. Eventually, full physical care will be necessary in all cases. This is provided by nurses, volunteers (in the hospice or at home) and/or relatives. If relatives take on some or all of the care, proper instruction by the nurse is very important.

The patient's comfort is paramount. In consultation with the patient, the wishes and expectations regarding care and/or nursing are agreed upon. In the care plan, agreements are recorded regarding the way in which care and/or nursing is provided (washing, dressing, changing the bed, products to be used (such as impregnated wash cloths and care products) and, if necessary, changing bed position).

During preparation, a high-low bed has already been provided (so that care by others is easily possible). If necessary, an anti-decubitus mattress, an anti-decubitus cushion for the chair and/or heel protectors are used.

Good skin care is important. In case of pressure sores or other skin problems, a specialized nurse can be consulted. See the national Decubitus Directive and Pressure Sores Directive from the Dutch Nursing Society. Obviously, some routine nursing procedures (e.g. taking temperature or blood pressure) are omitted.

5.7.3 Mouth care

The feeling of thirst or dry mouth is caused by dehydration of the mucous membranes of the oral cavity. Good oral care is essential to prevent symptoms of dry mouth and feelings of thirst as much as possible. It is started at a time when the patient is not yet bothered by it. Initially, the patient may still be able to take care of her mouth herself, but gradually she will become more and more dependent on others. If at all possible, relatives are involved in oral care, as they are often present with the patient most of the time. Good instruction is then required.

At least once a day, the mouth is thoroughly inspected by a healthcare provider to detect oral problems early. This requires good lighting (torch), gloves and (wetted) tongue spatulas or gauzes. Systematic inspection of the lips, cheek mucosa, tongue, mouth floor, gums and teeth or dentures is performed. If necessary, an oral status score can be used.

Oral care is performed several times a day and includes, for example:

- refreshing the mouth using:
 - a water nebulizer (small plant sprayer or cologne bottle); three puffs contain about 2 cc of water (as often as desired);
 - half an ice cube, splintered and wrapped in a gauze, which can be sucked on; this contains about 5 cc of water (as often as desired);
 - licking a sugar-free lolly pop;
 - for bad breath: mint-flavoured mouth spray or mouth spray with chlorhexidine, cetylpridinium chloride and zinc lactate (spray 2-3x a day on the tongue with 3-4 puffs);
- stimulating salivary secretion by using sugar-free chewing gum or sugar-free sweets (provided the patient is still able to chew or suck, respectively);
- the use of oral moisturizers or saliva substitutes (especially before sleeping, to avoid drying out the mucous membranes when sleeping with an open mouth). Have the relatives check whether these products are covered by the health insurance;

- rinsing the mouth with physiological salt (dissolve one level teaspoon of salt in a glass of lukewarm tap water, 4 times daily, more often if necessary) or 0.12% chlorhexidine; after rinsing, the mouth rinse is spat out again. If the patient is no longer able to rinse the mouth, the mouth can be rinsed with physiological salt or chlorhexidine 4 times a day (more often if necessary) using a syringe. The mucous membrane of the mouth and tongue can also be wetted with a moist gauze, cotton swab or dental swabs;
- keeping lips greasy using petroleum jelly or lip cream (two times daily, more often if necessary);
- brushing the teeth with a soft, preferably electric toothbrush (two times daily);
- cleaning between the teeth (interdental) using interdental brushes, toothpicks or floss (once a day);
- cleaning the dentures. The dentures may (partly depending on the patient's wishes) initially be kept in during the day, for reasons of appearance and also to make speaking easier. If the patient does not like it (anymore) or if there are oral problems, the dentures are also left out during the day.
- tongue brushing (if necessary, once a day); a soft toothbrush or tongue cleaner can be used for this purpose.

When people breathe through their mouths, the mouth may dry out during sleep. If necessary, a steam device can then be used above the bed, close to the mouth.

Most of the required materials are not covered by health insurance and are available at drugstores.

A candida infection can be recognized by a hyperemic mucosa, usually with a white mash and/or white speckles on the oral mucosa and/or tongue. Then, depending on the symptoms and life expectancy, treatment can be initiated with:

- fluconazole suspension or tablets 100 mg once daily mg for 7 days (if the patient is still able to take oral medication); or
- miconazole gel 20 mg/g 4 times daily 1 measuring spoon, to be applied with the finger or a cotton swab. The use of nystatin suspension is not recommended due to its taste, the amount of liquid and the need for frequent administration.

For further information, see the Guideline Oral complaints in the palliative phase and the Guideline Oral care for care-dependent clients in nursing homes from the Association of Elderly Care Physicians.

5.7.4 Guidance of the relatives

At all stages of the process, the burden on relatives can be high, especially if it takes a long time, the care is intensive, the patient is difficult to approach or cared for, and/or the relatives have difficulty with the patient's decision. In such cases, there is a (high) risk of physical and emotional overload for the relatives.

Signs of overload may include:

- stress reactions, such as headaches, insomnia, lack of appetite, tension, nervousness and depression; in severe cases, there may be negative cynicism, emotional lability, anger, verbal or physical aggression or aversion to the situation;
- use of (too) many sleeping aids or sedatives;
- increase in smoking and/or alcohol consumption;

- guilt or feelings of falling short;
- physical complaints, especially of the musculoskeletal system.

Good information to and instruction of relatives regarding care are essential throughout the process. Relatives should have the opportunity to rest or sleep (e.g. by deploying professional caregivers or volunteers at night) and (if desired) also to be able to withdraw from care for a while during the day and leave the home or institution. The starting point in supporting the relatives is that the caregiver anticipates the problems that may arise sooner or later for the relatives. To this end, regular meetings are held with relatives in which the following issues are (or may be) raised:

- feelings about the patient's decision;
- their own role in the process;
- burden and capacity to cope;
- the presence of the above cues;
- (dis)satisfaction with the care provided by professional caregivers and/or volunteers;
- need for (more) support;
- worry and fear of what is to come.

In counselling the relatives, a spiritual caregiver can also play an important role.

5.7.5 Caring for professional carers

Caring for a patient who voluntarily refrains from eating and drinking can also be stressful for professional carers and volunteers. Good information, good communication between professional carers and volunteers, and optimal coordination of care are essential to make the process run smoothly and minimize the burden on carers. Attention should be paid to the emotions of all caregivers involved (including volunteers) during the process. This can be done by meeting at regular intervals, e.g. every two to three days, to share experiences and emotions. This can vary from a consultation between GP and home care, to an extensive multidisciplinary consultation in the nursing home or hospice, in which the spiritual caregiver can also be involved.

A conversation after the patient's death can reflect on the course of events and the emotions and questions that the process raised in the professional caregivers and volunteers involved.

5.8 Executive phase: middle phase

The duration of the middle phase is variable. Depending partly on the severity of any disease present, this phase (with minimal fluid intake) usually lasts no longer than 1-2 weeks. If the patient does not limit drinking to a minimum (< 50 ml/24 hours), it may take days to weeks longer before death. Furthermore, the length of the period is determined by the patient's physical condition at the time she stops eating and drinking.

If the patient has stopped eating and drinking little or no more, increasing weakness and bedriddenness occur in this phase. Relatives and/or professional caregivers are then usually continuously present for physical care, oral care, support and guidance, and also to prevent the patient from falling when trying to get out of bed.

This period can be very important and enriching for relatives on the one hand, but can also be very stressful on the other. Support and guidance of relatives are very important. For professional caregivers, this can also be a stressful period. They too need attention.

In this phase, increasing dehydration will occur. Various symptoms and problems may occur, such as thirst, dry mouth, problems with micturition and defecation, pain, nausea/vomiting, agitation, confusion and delirium. If in the course of the process there is an untreatable (refractory) symptom that gives rise to intolerable suffering, intermittent or continuous palliative sedation may be started.

In the following, the aspects mentioned above will be discussed. Naturally, other complaints and problems may also occur in this phase, especially if they were present beforehand. For information on the treatment of these other complaints and problems, please refer to the Palliative Care Guidelines.

5.8.1 Dehydration

During this phase, dehydration will increasingly occur. This may have both favourable and unfavourable effects on a number of pre-existing symptoms and problems or (if not present) on the likelihood of their occurrence (see Guideline on dehydration and fluid administration in the palliative phase).

Beneficial consequences may include:

- less urine production, resulting in fewer toilet visits, decrease in urinary incontinence and less likely need for a bladder catheter;
- less sputum production, resulting in less coughing;
- less vomiting and less diarrhoea;
- decrease in peripheral oedema, ascites, pulmonary oedema or cerebral oedema;
- less pain due to reduction of oedema around the tumour.

Adverse consequences may include:

- dry mouth and thirst;
- increased risk of urinary tract infections;
- dry mucous membranes;
- sticky mucus;
- constipation;
- accumulation of medication excreted through the kidneys, increasing the risk of side effects;
- greater risk of confusion and delirium.

5.8.2 Problems with micturition and defecation

Urinary output will usually decrease significantly over time. As long as the patient is able to do so, use of the toilet or toilet chair is preferred. When the patient is (or has become) completely bedridden, the following may be used:

- a bedpan or urinal;
- incontinence material or a mat;
- a condom catheter (in a male) or indwelling catheter.

For further information on micturition problems, see the the guideline Urogenital Problems Guideline.

Regarding defecation, giving a phosphate enema once can be considered if the patient stops eating and drinking. If no defecation occurs subsequently, giving 10 mg bisacodyl supp. every

other day may be considered. Usually, defecation occurs within 30-60 minutes of administration. If it does not, rectal examination can be performed. If faecal impaction is present, a phosphate enema is given or possibly the stool is removed digitally (with the finger) by the nurse or doctor.

For further information, see the Guideline Constipation in the Palliative Phase.

5.8.3 Pain

In some cases, the patient is already taking painkillers as a maintenance treatment when she decides to refrain from eating and drinking. Naturally, pain medication is then continued, with the dose being tuned (changed if necessary) according to the intensity of the pain. If the medication is administered orally, sooner or later conversion to another route of administration is indicated (see table 5.1). The use of a pain score or observation list is recommended.

Paracetamol can be administered rectally, usually at a dose 1000 mg rectally 3 times daily. NSAIDs (diclofenac and naproxen) can be administered (in the same dose as orally) as suppositories, but their use is not recommended. The reasons are the usually advanced age of the patient and the fact that dehydration is likely to worsen renal function at this stage, increasing the risk of side effects (gastrointestinal symptoms, delirium).

Maintenance treatment with morphine is not recommended because it is excreted by the kidneys and therefore there is a risk of accumulation, with a high(er) risk of side effects. Therefore, fentanyl patches, combined with a laxative, e.g. bisacodyl rectally, are preferred Slow release morphine and oxycodone can be administered rectally, but this route of administration is not preferred for several reasons.

Alternatives are intermittent administration of opioids on a fixed schedule or continuous subcutaneous infusion of opioids using a pump, but this will rarely be necessary. For reasons previously mentioned, the use of morphine is not recommended and it is better to opt for continuous infusion of oxycodone. See table 5.2 for conversion factors when opioids are used.

Table 5.2 Conversion table opioids

<u>Morphine</u>		<u>Fentanyl</u>	Oxy	codone	Hydron	norphone	<u>Tramadol</u>	<u>Buprenorphine</u>	<u>Tapentadol</u>
orally	s.c./i.v.	patch	orally	s.c./i.v.	orally	s.c./i.v.	orally	patch	orally
mg per 24 hrs	mg per 24 hrs	μg per hr	mg per 24 hrs	μg per hr	mg per 24 hrs				
30	10	12	20	10	61	2	150		
60	20	25	40	20	12	4	300		150
120	40	50	80	40	24	8	_2	52,5	300
180	60	75	120	60	36	12	-		4
240	80	100	160	80	48	16	-	105	
360	120	150	240	120	72	24	-	_3	
480	160	200	320	160	96	32	-	-	

¹ This dose cannot be given in clinical practice as the lowest dose of the slow release tablet is 4 mg and this needs to be given twice a day.

During maintenance treatment with opioids, medication should be available to treat breakthrough pain. As these are incidental administrations, there is no objection to the use of morphine here. For the treatment of breakthrough pain the following may be given:

- immediate release morphine:
 - orally (drink) or rectally (both at a dose of 1/6 of the oral daily dose; when fentanyl is used transdermally, 1/6 of the corresponding oral daily dose of morphine is given, see table 5.2);
 - subcutaneously or intravenously (also 1/6 of the daily dose);
- immediate-release oxycodone orally (tablet or drink) or subcutaneously/intravenously (both also at a dosage of 1/6 of the daily dose (whether converted or not);
- fast-acting fentanyl. For all fast-acting fentanyl preparations, start with the lowest dose (i.e. independent of the dose of the maintenance medication).

See Table 5.2 for the opioid conversion factors.

Even if the patient is initially in no pain, painkillers are prescribed and self-managed by the patient. Due to prolonged lying in bed and sometimes skin problems, pain symptoms may occur during the process. Initially, paracetamol suppositories (1000 mg supp. up to 4 times daily, if necessary) may suffice. If the oral and rectal routes of administration are not possible or undesirable or these have insufficient effect, fentanyl 100 ug sublingually or 50 ug intranasally, immediate-release morphine 5-10 mg rectally, or 2.5-5 mg subcutaneously or intravenously) or immediate-release oxycodone 2.5-5 mg subcutaneously or intravenously) may be given. If the effect is insufficient, the dose is increased.

Especially in patients who have not used opioids before, side effects may occur, such as drowsiness, constipation, nausea/vomiting, (worsening of) dry mouth and delirium.

For further information, see the guidelines (in Dutch) Pain in patients with cancer in the palliative phase, Pain in advanced stages of COPD or heart failure and Palliative care in heart failure.

² Higher dosages than 400 mg daily are not recommended.

³ Higher dosages than 140 microg/hour daily are not recommended.

⁴ Higher dosages than 400 mg/24 hrs have not been studied.

5.8.4 Nausea and vomiting

Nausea and/or vomiting may occur as a side effect of medication (especially opioids), in association with constipation or as a manifestation of the consequences of an underlying disease (e.g. impaired gastric emptying, ascites or obstruction of the stomach or intestines).

Initially, metoclopramide 10 mg 3-4 rectally or subcutaneously 3-4 times daily, or haloperidol 0.5-2 mg (5-20 drops) two times daily is given buccally or subcutaneously. In case of insufficient effect, levomepromazine 6.25 mg is given subcutaneously or buccally. Dexamethasone (as an anti-emetic) is in principle not given because of its appetite-promoting effects.

For further information, see the Guideline on nausea and vomiting in the palliative phase.

5.8.5 Restlessness, confusion and delirium

Restlessness can be caused by:

- symptoms that are insufficiently controlled (e.g. pain or shortness of breath);
- full bladder or full rectum;
- bladder cramps due to a bladder catheter;
- overstimulation, e.g. due to too many people at the bedside;
- anxiety;
- side effects of medication (e.g. metoclopramide, dexamethasone or benzodiazepines);
- withdrawal of medication (especially opioids, corticosteroids, benzodiazepines), alcohol, nicotine or drugs;
- delirium.

Delirium is characterised by:

- disturbance of consciousness (reduced awareness of surroundings);
- disturbance of attention (an impaired ability to direct, focus, hold and shift attention);
- alteration of cognitive functions, such as disturbances of memory, in orientation in place and time, and in thinking and perception (delusions and/or hallucinations).

Symptoms arise over a short period of time, vary throughout the day and are often most pronounced at night. Delirium may be accompanied by agitation (hyperactive delirium) and/or apathy (silent delirium). Delirium is often preceded by early signs, such as disturbances of the day-night rhythm, unpleasant dreams, disturbances in concentration and attention, disorientation in time and place, hypersensitivity to light and/or sound, suspiciousness or hallucinations.

Delirium occurs relatively frequently in patients who voluntarily stop eating and drinking due to:

- the often advanced age of the patient;
- dehydration;
- medication (especially opioids);
- approaching death.

Delirium is a very unpleasant experience, not only for the patient herself, but also for relatives and caregivers. It is important to recognize and treat delirium early. Because delirium can fluctuate greatly during the day and night, observations by nurses and relatives are very important. The Delirium Observation Scale (DOS, see Guideline Delirium in the palliative

phase) may be used. This involves scoring 3 times daily based on observations by the nurse. If the score is low, delirium is unlikely. A score of 3 may indicate delirium, but is not conclusive. The diagnosis is made by a doctor based on the clinical picture.

Delirium in the last stage of life can sometimes be prevented by:

- providing landmarks (clock, pictures in the room, familiar faces at the bedside);
- avoiding too many stimuli (sound, images) at the same time;
- the use of glasses and/or hearing aids;
- not suddenly discontinuing opioids, benzodiazepines or corticosteroids, especially at high doses and/or long-term use;
- putting on a nicotine patch in patients who have smoked a lot.

The best treatment of delirium is treatment of the precipitating factor(s), e.g. by change of medication, treatment of infections (e.g. a urinary tract infection) or treatment of urinary retention. However, in a patient who has stopped eating and drinking, treatment of the precipitating factors is often not an option. Occasionally, a urinary tract infection can be treated with a single administration of phosphomycin. In case of urinary retention, a catheter is inserted. If opioids are the trigger for delirium, opioid rotation (replacing one opioid with another) or sometimes dose reduction are an option.

In the context of the patient who has stopped eating or drinking, a special situation may arise when the patient asks for fluids in her delirium (Quill 2018-1). In that situation, the patient will usually be incompetent with respect to the decision to resume drinking. If drinking is then asked for intrusively and repeatedly by the patient in an incompetent state, a difficult situation may arise. On the one hand, it may be very difficult to refuse this request; on the other hand, the relative or professional caregiver may want to stick to the agreements made with the patient when she was still able to exercise her will. In such a situation, agreements made about this in the preparatory phase and/or the written advance directive can be referred to (see section 5.6.4).

It is crucial that, especially when a difficult situation arises, healthcare providers do not simply cancel the arrangements with the patient (who then shows involuntarily behaviour), change policy and start administering fluids. With the administration of fluids, the patient cannot achieve her own desired goal. Therefore, prevention and treatment of delirium through the non-pharmacological measures described below are important, as well as an anticipatory policy with 'if necessary' medication in case of agitation and delirium.

Non-pharmacological measures are an important part of treatment. These are the same measures as mentioned in prevention. The aim is to create a calm, stable and safe environment. The continuous presence of a relative can play an important role in this situation. Explaining to relatives about the state and how to deal with it is important. It is important to communicate calmly and clearly with the patient and not to act against delusions or hallucinations. It should also be stressed that there is no point in addressing the patient or making agreements In many cases, the patient should be considered incompetent at the time of delirious symptoms. Extreme protective measures against climbing out of bed and falling (such as bed rails and restraints) are often counterproductive and are only taken in an extreme emergency and only after explanation to and consent from the representative.

For drug treatment, refer to the Dutch Guideline Delirium in the Palliative Phase (www.palliaweb.nl) and the Guideline Delirium in Adults and the Elderly of the Dutch

Society for Clinical Geriatrics. Haloperidol is the drug of first choice. However, given the dehydration and short life expectancy, treatment with haloperidol is often quickly combined with benzodiazepines or the use of palliative sedation.

5.8.6 Palliative sedation

If a patient who stops eating and drinking is suffering unbearably due to one or more symptoms that cannot be controlled (otherwise) (so-called refractory symptoms), palliative sedation may be considered (see section 2.8 and section 4.5).

Reviews mention the (proportional) use of palliative sedation as an option during the process of VSTED (Gruenewald 2018, Den Hartogh 2020, Lowers 2021-1, Schwarz 2009, Wax 2019). The committee sees no reason why palliative sedation should not be deployed during the course of VSTED if there is unbearable suffering due to a refractory symptom.

A symptom is refractory if none of the conventional treatments are effective (sufficiently quickly) and/or these treatments are associated with unacceptable side effects (Palliative sedation guideline). For continuous palliative sedation, an estimated time to death of up to two weeks is a prerequisite. This condition does not apply to intermittent or one-off short-term palliative sedation. The advantage of this is that communication is still possible at other times. Especially in the case of difficult and restless nights (despite sleep medication), intermittent sedation can be used as a first step.

A patient who has stopped eating and drinking often experiences exhaustion and/or delirium, but sometimes (also) thirst that persists despite good oral care. There is then a refractory situation for two reasons. First, the patient has not consented to fluid delivery or artificial hydration (and therefore the symptom is untreatable). Second, taking fluids leads to a highly undesirable prolongation of life for the patient, which thus may be considered an unacceptable side effect in this context.

Moreover, the Palliative Sedation Guideline indicates that if existential suffering can no longer be relieved by, for example, conversations or spiritual support, this suffering may also be refractory. Existential suffering may thus be part of the refractory symptoms that lead to unbearable suffering of the patient. In the context of a patient who has voluntarily stopped eating and drinking, existential suffering may also play an important role. In many cases, the use of palliative sedation during the process of VSTED involves a combination of agitation or delirium, exhaustion, thirst and existential problems, which give rise to unbearable suffering.

Continuous palliative sedation can and should be initiated only when the patient has shown that she consistently refrains from eating and drinking. A period of at least several days, during which the patient has had little or no drinking, is a requirement for this. In that case, the condition of an estimated time to death of up to two weeks is met. If there is doubt about the consistency of the decision to refrain from eating and drinking, continuous sedation is not appropriate (yet). For this reason, continuous palliative sedation is not initiated immediately at the moment the patient actually stops eating and drinking.

Palliative sedation is applied proportionally. That is, the degree of decrease in consciousness that is necessary and sufficient for the desired degree of symptom relief is pursued. The measure of effect is patient comfort and not the degree of decrease in consciousness. In some cases, a slight degree of decrease in consciousness is sufficient to relieve suffering (superficial

sedation). In that case, the ability to communicate is preserved. In practice, deep sedation is often used, resulting in the loss of the ability to communicate.

In principle, the use of palliative sedation requires the consent of the patient or (in cases of incapacity, e.g. due to delirium) the representative. In acute situations (when the patient is incompetent and there is no time to ask the representative for consent), palliative sedation can be initiated without consent. However, this situation will almost never arise in the trajectory of VSTED.

It is important to stress in the education of patients and relatives that palliative sedation does not hasten death, if applied in accordance with the guideline.

For the treatment schedule and doses of medication to be used, see the Palliative sedation guideline. If a patient was already treated with opioids and/or antipsychotics, this medication is continued, but only to control pain, dyspnoea or delirium. For pain or delirium, levomepromazine may be used early in addition to midazolam. In case of pain, opioids are then continued; in delirium, haloperidol can then be discontinued.

5.9 Executive phase: dying phase

The dying phase is the phase immediately preceding death, when death presents itself inescapably. The patient is expected to die within a few days. The course of the dying phase of patients who have deliberately stopped eating and drinking is essentially no different from patients who die as a result of a life-threatening illness.

The assessment that the dying phase has arrived is done mainly on the basis of good observation and clinical experience. Because nurses have more intensive and frequent contact with the patient, they often recognize that the dying phase has arrived earlier than the doctor.

Signs of impending death are:

- severe fatigue and debilitation, leading to complete bedriddenness;
- reduced urine production;
- fast, weak pulse;
- cold to the touch, sometimes cyanotic extremities and appearance of lividity spots;
- pointed nose (the skin over nose and cheekbones tightens);
- diminished consciousness and eventually often complete loss of consciousness;
- increasing disorientation, sometimes accompanied by hallucinations and terminal restlessness;
- death rattle;
- irregular breathing shortly before death (Cheyne-Stokes breathing).

It is important to inform not only the patient (if still approachable) and relatives that the dying phase has arrived, but also the professional caregivers and volunteers involved. The conversation with relatives should include:

- their reactions and emotions following the onset of the dying phase;
- what symptoms and problems to expect and how to deal with them; mentioning that death rattle and Cheyne-Stokes breathing often occur before death, but that the patient does not experience shortness of breath in the process;
- vigil at the patient's bedside;
- desired rituals, appropriate to ideology/religion and culture;

- desired/necessary (additional) use of caregivers or volunteers;
- what to do if the patient has died.

The patient's physical care and treatment of symptoms are not substantially different from the care and treatment described in the middle phase. Attention to good oral care is even more important than in the previous period, as the patient is no longer able to do it himself and often lies with an open mouth for long periods.

Delirium is more likely to occur in the dying phase than in the period before. Early recognition of (symptoms of) delirium and its treatment are essential. A potential pitfall here is the occurrence of agitation in a patient treated with opioids. It is quite common for agitation to be interpreted as a consequence of insufficiently controlled pain or shortness of breath, and therefore additional opioids are given and/or the dose of opioids is increased. In many cases, such agitation is a manifestation of terminal delirium and giving extra or increasing opioids will only increase the agitation. Consideration should then be given to reducing the dose of opioids (if there is room for it) or rotating to another opioid. Furthermore, if agitation occurs, the possibility of urinary retention or constipation should always be considered.

For further information, see the Guideline on Care in the dying stage.

The death of a patient who has voluntarily stopped eating and drinking is considered a natural death. The death papers are completed in the usual way, naming 'stopping eating and drinking' as the immediate cause of death. There is no reporting requirement and the municipal coroner need not be involved.

All involved healthcare providers are informed of the patient's death. In principle, an evaluative follow-up interview is then organized with the caregivers involved. An evaluative follow-up discussion is also held with the family and relatives.

Part 3 Stopping offering food and drink in incompetent patients with dementia

6. Stopping offering food and drink to incompetent patients with dementia¹⁶

6.1 Summary

- In some situations, in incompetent patients with dementia, it may be questioned whether food and drink should still be offered.
- This discussion may stem from an advance directive or a documented oral expression of the patient's will, when the patient was still competent in this matter. This discussion can also be entered into by the representative or by the healthcare providers involved, without an advance directive or documented oral expression of will by the patient.
- The behaviour shown by the patient with dementia with regard to eating and drinking can range from more or less normal eating and drinking (positive verbal and/or non-verbal cues), with or without support from a relative or caregiver, to defensive behaviour (defined as: any behaviour of a patient that interferes with or prevents eating or drinking).
- Nursing and care are considered medical acts according to the Dutch Medical Treatment Agreement Act (WGBO). Eating and drinking are part of that. Refusing food and fluids as part of daily care can therefore also be considered a refusal of treatment. This treatment refusal may be recorded in an advance directive or expressed verbally.
- A treatment refusal will be respected unless there is a 'legitimate reason' to deviate from it. The judgement on 'legitimate reason' lies with the healthcare providers involved.
- The following factors may or may not play a role in the decision to stop offering food and drink:
 - o patient-related factors:
 - The patient's behaviour towards eating and drinking is the most important factor for decision-making.
 - Observable suffering is not a prerequisite, but it is a factor that can be taken into account when deciding to stop offering food and drink. Stopping offering food and drink can therefore be professionally justified even in the absence of observable suffering.
 - The judgment of the representative and/or healthcare providers on the patient's quality of life is a highly subjective and debatable criterion, on which consensus will often be impossible to reach. Therefore, it cannot be used as a criterion in practice.
 - o the representative's view (also on behalf of relatives);
 - o the view of the healthcare providers involved;
 - the presence or absence of an advance directive or documented oral expression of will. The absence of these does not preclude stopping offering food and drink.
- A decision to stop offering food and drink in such a situation can only be made after a careful process. Components of the decision-making process may include consulting relevant experts (for example, an elderly care physician, a clinical geriatrician or an internist in geriatrics) and/or holding a moral deliberation.
- The decision to stop offering food and drink is made by the responsible professional caregiver, after consultation with the representative and in coordination with the other professional caregivers involved.
- Patient behaviour is leading in decision-making. The presence of an advance directive or documented oral expression of will plays a limited role.

¹⁶ Chapter 6 of the Dutch version (describing experiences with VSTED of patients, relatives and professional caregivers) has been omitted in the English translation).

- If the patient gives positive verbal and/or non-verbal cues with regard to eating and drinking, the offering of food and drink is not stopped, even if an advance directive or documented verbal expression of will is present. The discrepancy between the content of the advance directive and the observed behaviour is considered a valid reason to deviate from the advance directive. Moreover, caregivers cannot be expected/required to withhold food and drink from a person who gives positive verbal and non-verbal cues regarding eating and drinking.
- If there is consistent and not (easily) treatable defensive behaviour and an advance directive or documented oral expression of will is present, it is professionally justified to stop offering food and drink. Permission from the representative is desirable in this regard, but not strictly necessary. Even in the case of defensive behaviour without an advance directive or documented verbal expression of will, it may be professionally justified to stop offering food and drink. In this situation, the decision to stop offering food and drink can only be made if there is consensus between the representative and the responsible caregiver.
- In the intermediate range (no positive verbal and/or non-verbal cues towards eating and drinking nor defensive behaviour), stopping offering food and drink can only be considered in extreme cases, if there is an advance directive or a documented verbal expression of will and preferably with the consent of the representative.
- The table below schematically answers the question when it is professionally justified to stop offering food and drink to an incompetent patient with dementia. In each box marked '- ', stopping offering food and drink is not professionally justified. In the situations marked '++', '+' or '+/-', stopping offering food and drink is to a greater or lesser extent professionally justified.

Decision to stop offering food and drink	Opinion of representative (without advance directive or documented oral expression of will)#	Opinion of responsible caregiver (without advance directive or documented oral expression of will)#	Verbal will documented in medical record#	Advance directive#
Positive verbal and non-verbal cues regarding eating and drinking	-	-	-	-
No verbal and non-verbal cues regarding eating and drinking, but also no defensive behaviour	-	-	+/-	+/-
Defensive behaviour	+* -**	+* -**	++	++

In which the patient indicates not wanting to be offered food and drink.

++, + or +/- Stopping offering food and drink is professionally justified to a greater or lesser extent.

Stopping offering food and drink is not professionally justified.

By consensus between representative and responsible caregiver about stopping offering food and drink.

** In case of disagreement between representative and responsible caregiver.

6.2 Introduction

This chapter discusses decision-making around stopping offering food and drink to incompetent patients with dementia. ¹⁷ A conversation about this may arise based on the following situations:

- 1. The patient has included in an advance directive that, when she has become incompetent in this respect (see also section 2.3), she wishes to forgo food and fluids. In such a will, the patient may write down that she wishes to forgo artificial nutrition and fluids at that time, but also that she no longer wishes to be offered food and drink from then on. She may see this as an opportunity to retain as much control over her own life as possible beforehand, should she find herself in a condition that is unacceptable to her.
- 2. When she was still able to exercise her will, the patient made verbal expressions of will about stopping offering food and drink to relatives and/or healthcare providers that were recorded in the medical record.
- 3. The representative in consultation with the relatives questions the cessation of the offering of food and drink on the basis of undocumented verbal expressions of the patient's will or on the basis of her conception of what the patient would have wanted and/or what is in the patient's best interest at that moment, without a previous advance directive or documented verbal expressions of the patient's will being present.
- 4. The responsible caregiver in consultation with the other caregivers involved questions the cessation of offering food and drink without an advance directive or documented verbal expressions of the patient's will.

Stopping the provision of food and drink can present legal, ethical and/or practical dilemmas for caregivers and relatives. This chapter first outlines the background of the topic and provides information on the target group of this chapter, patients with dementia, and the impact of dementia on eating and drinking. This is followed by a description of the legal context of decision-making around stopping offering food and drink. Finally, a discussion of the factors involved in decision-making and its consideration follows.

The chapter provides a framework within which healthcare providers can weigh whether stopping offering food and drink to an incompetent patient with dementia is permissible and, if so, under what circumstances. To the committee's knowledge, there are no Dutch or foreign guidelines that discuss stopping offering food and drink to patients with dementia.

6.3 Background

6.3.1 Target group

People can become incompetent during the course of their lives, for example due to an illness or an accident. In practice, this often involves people with dementia. With dementia, it can be anticipated that cognitive functions will decline in the future and that the patient may become incompetent at some point. This perspective is often not present with many other diseases and accidents, as the incompetence then often occurs suddenly and unexpectedly.

¹⁷ There is no VSTED in these situations because a person who is (or has become) incompetent cannot voluntarily stop eating and drinking (anymore). If this is done on the basis of an advance directive, the international literature refers to Stopping Eating and Drinking by Advance Directives (SED by AD) (Christenson 2019, End of life Choices New York 2022, Marks 2020, Trowse 2019, Volicer 2016 and 2019, Wright 2019). Patients with dementia who have become incompetent after the (voluntary) decision to stop eating and drinking are beyond the scope of this chapter.

This chapter relates to people with dementia who have become incompetent with regard to the decision to voluntarily stop eating and drinking.¹⁸ Incompetent means that a person 'cannot be considered capable of a reasonable appreciation of her interests with regard to a decision or situation at issue' (KNMG 2004, p. 91, see also section 2.3). The considerations discussed in this chapter may also apply to patients with other conditions who have become incompetent. Patients who have been incompetent throughout their lives due to intellectual disability are outside the scope of this chapter. These people have never been able to express or establish their will.

6.3.2 Distinctions with regard to stopping nutrition and hydration in incompetent patients with dementia

Regarding the cessation of nutrition and hydration in incompetent patients with dementia, a distinction is made between:

- 1. stopping offering food and drink when the patient is still able to eat and drink independently;
- 2. not (or no longer) helping with eating and drinking, if the patient needs help from a relative or caregiver to do so;
- 3. discontinuing or not starting artificial nutrition and/or fluid administration (by tube, intravenously or subcutaneously).

The text further designates the situations discussed under 1 and 2 as 'stopping offering food and drink'. Where necessary, the distinction is made.

In the Netherlands, long-term tube feeding and parenteral nutrition (as mentioned under 3) are only rarely used in patients with dementia. Their discontinuation therefore occurs relatively rarely in practice and is not discussed further here. Not starting artificial nutrition and hydration is also outside the scope of this guideline, as is forcible administration of nutrition and/or hydration (e.g. in the context of involuntary care).

6.4 Disease progression in dementia and the possible impact on eating and drinking

6.4.1 Disease course in dementia

Dementia generally has a long-term course (usually in the order of 5-10 years) and is preceded by a period of cognitive deterioration ('mild cognitive impairment') during which there is no dementia (yet) (Quill 2021). The course (both in terms of symptoms and duration) varies from patient to patient and depends partly on the type of dementia. Whether and when incapacity occurs is highly variable and varies from patient to patient and situation to situation.

6.4.2 Problems with eating and drinking in patients with dementia

Problems with eating and drinking in people with dementia can occur due to:

- physical complaints and problems (e.g. pain, stomatitis or swallowing problems);
- not being able/not knowing how to eat (as a form of apraxia) in the context of cognitive
 decline; this may include not knowing how to get the food to the mouth or not knowing
 how to chew or swallow;
- increasing metabolic dysregulation in the context of anorexia-cachexia syndrome, as occurs in other life-threatening diseases (Guideline Anorexia and Weight Loss). As a

¹⁸ In the remainder of this chapter, the term 'in respect of' will be omitted. Wherever 'incompetent by will' is mentioned, it means 'incompetent in respect of the decision to stop eating and drinking'.

result, patients develop less appetite, gradually start eating less and lose weight. Eventually, nutrition will not cover the body's needs and weakening, bedriddenness and death occur. Here, not eating is a consequence of the disease and not the cause of death. Besides, fluid intake is maintained much longer than dietary intake.

Also in relation to the above problems, three situations can be distinguished regarding the behaviour of patients with dementia with regard to eating and drinking:

- 1. A patient with dementia gives positive verbal and/or non-verbal cues regarding eating and drinking. She then does eat, with or without the help of a relative or professional caregiver.
- 2. Eating and drinking are associated with defensive behaviour. Defensive behaviour refers to 'any behaviour of a patient that interferes with or prevents eating or drinking' (Groenewoud 2009). Repelling eating and drinking occurs in many different forms (see table 1).

Table 1. Examples of defensive behaviour

Pre-meal:

The resident:

- refuses to go to the room where food is being eaten.

During meals:

The resident does not take a bite or a sip:

- refuses verbally (I don't want to);
- doesn't touch the food;
- pushes his spoon or plate away, or (the hand of) the carer;
- bites on the spoon;
- turns his head away;
- keeps his mouth shut;
- holds his molars together;
- walks away from the table.

The resident takes a bite or sip, but does not swallow:

- gags;
- spits out the food or drink;
- takes the food out of his mouth with his hands;
- does not swallow the food or drink.

Groenewoud JH, Lange J de. Guideline dealing with defensive behaviour in eating and drinking in residents with dementia. Knowledge Circle Transitions in Care, Rotterdam University of Applied Sciences, 2009.

Which cues from the patient are considered as defensive behaviour depends on the patient's health status and functioning. This will have to be assessed on a patient-by-patient basis. For example, if someone has swallowing problems due to a CVA, not swallowing solid food cannot be interpreted as defensive behaviour.

Defensive behaviour can have several causes, which may be treatable. The Guideline Dealing with Defensive Behaviour in Residents with Dementia provides further guidance on how to deal with the diagnosis and treatment of these problems in patients with dementia (Groenewoud 2009). This guideline is intended for level 3 nurses in nursing

homes, but is also useful for doctors and other nurses in nursing homes, at home or in the hospital setting. The guideline does not give advice on stopping offering food and drink.

Defensive behaviour will always require assistance and sometimes persuasion with eating and drinking by the relative or professional caregiver. The question then arises of how far one can and should go with attempts to feed. If caregivers actually try to get food and drink inside, a gradual transition to involuntary care occurs. ¹⁹ Involuntary care is only allowed if there is 'serious harm' and there are no other solutions/alternatives to treatment. This will have to be assessed on a case-by-case basis in accordance with legislation (the Dutch Care and Compulsion Act). In practice, involuntary care with regard to nutrition and fluids is only extremely rarely applied in patients with dementia.

3. Between 'normal eating' and defensive behaviour lies intermediate area, in which the patient does not give positive cues regarding eating and drinking, but also does not show defensive behaviour. In this case, help from a relative or professional caregiver with eating and drinking will always be necessary, because the patient will not eat or drink on her own if it is put in front of her.

Behaviour towards eating and drinking is an important factor in decision-making (see section 6.6 and section 6.7).

6.5 Legal context

Offering food and drink is a daily part of nursing and caring for patients. Food and drink are necessary to sustain a patient's life. Refraining from offering food and fluids in a caredependent situation without justification is not acceptable and would also constitute a criminal offence.²⁰

This means that stopping offering food and drink in such a situation must always be justified. However, it may be part of good care in some situations to not offer food and drink (anymore).

6.5.1 Treatment refusal

A competent person may indicate which treatment or care she does not want (or no longer wants) in the future, in case she can no longer determine her will (so-called treatment refusal). This includes, for example, resuscitation or other life-extending treatment. Nursing and care are considered medical acts according to the WGBO (Article 7:466 paragraph 3 of the Dutch Civil Code). Eating and drinking are part of this. Refusing food and fluids as part of daily care can therefore also be regarded as treatment refusal. This treatment refusal may be set out in a advance directive or expressed verbally. These expressions of will only apply once a person can no longer determine her will. If the patient can still do so, then the current will applies.

According to the WGBO, the healthcare provider must respect a written advance directive containing a refusal of treatment, unless there are legitimate reasons to deviate from this, ²² for

²¹ Treatment refusal involves a negative will. In it, the patient describes what care or treatment she no longer wishes to receive t in a given situation. In a positive advance directive, a patient requests the doctor to perform certain actions or initiate or continue treatment. See Declaration of wishes | KNMG.

¹⁹ Involuntary care is care to which the client or her representative does not consent or care to which the representative has consented but which the client opposes.

²⁰ Article 255 Penal Code

²² Article 7:450(3) BW.

instance in case of uncertainty about the authenticity, signature or content of the advance directive. The legislative history does not exhaustively list what should be understood by 'legitimate' reasons. In the Memorandum on the Legal Status of Wills in Health Care, the following was said about this: 'It is (...) not really possible to give a concrete, generally valid answer to the question of what reasons' for deviating from the will can be legitimate. Practice, and where appropriate the opinion of the (disciplinary) court, will have to show what legitimate reasons' may be to deviate from a advance directive'. ²³ The WGBO leaves the judgement to the counsellor (Leenen 2020).

In principle, a verbal expression of will addressed to a healthcare provider, documented in the medical record, has as much value as an advance directive. After all, what matters is that the patient has clearly stated that he does not consent to treatment in certain situations. An advance directive generally offers more clarity. Therefore, patients are advised to put wishes such as a treatment refusal in writing, clearly stating the situations in which the treatment refusal applies, to discuss them with their healthcare provider and to reaffirm or update the statement regularly, in any case if the patient's view or the situation has changed. This chapter assumes that the written advance directive is current at the time when stopping offering food and drink is being considered.

6.5.2 Representation

If a patient is not (or no longer) able to consent to treatment or other care ('is incompetent in this regard'), she is represented by another person. The representative acts 'in the spirit and best interests of the patient's'. See further section 4.9.

6.6 Considerations when stopping offering food and drink to patients with dementia

This section discusses factors that play a role in decision-making about stopping offering food and drink to incompetent patients with dementia. These include:

- patient-related factors;
- the view of the representative;
- the view of healthcare providers;
- the presence or absence of an advance directive or previous documented oral expressions of will.

Section 6.7 discusses the consideration of these factors in decision-making.

6.6.1 Patient-related factors

Patient behaviour towards eating and drinking

In the process of dementia, there can be wide variations with regard to eating and drinking. These range from active eating and drinking to consistent display of defensive behaviour (see section 6.4.2). In between, there may be reduced interest in eating and drinking. The nature and consistency of behaviour towards eating and drinking are the most important factors in deciding whether to stop offering food and drink.

If defensive behaviour is present, diagnosis of treatable causes should be made. Treatment of the causes of defensive behaviour is indicated if it is a simple, nonburdensome and potentially effective treatment (e.g. pureeing of food or treatment of candida stomatitis). Assessing the

²³ Parliamentary Papers II, 1990-2000, 26 885, no. 1, p. 9.

consistency of defensive behaviour and the effect of its possible treatment will generally take several weeks.

Observable suffering of the patient and/or a quality of life rated as poor by relatives and professional carers

The question is whether observable patient suffering and/or a quality of life rated as poor by relatives and professional carers should be allowed to play a role in decision-making.

The patient's behaviour (e.g. crying or shouting) may indicate that the patient is suffering severely. Observable suffering can be both psychological and physical, and be the result of the dementia or another concomitant condition. Such observable suffering is not a condition, but it is a factor that can be taken into account when deciding to stop offering food and drink. Stopping offering food and drink can therefore be professionally justified even in the absence of observable suffering. Defensive behaviour can also occur without observable suffering.

Even if there is no observable suffering, the patient's quality of life may be assessed as poor by relatives and/or professional carers. This may prompt a discussion about stopping offering food and drink. However, quality of life is a subjective and debatable criterion, on which consensus often cannot be reached and which can not be used as a criterion in practice. It is therefore not included in decision-making.

6.6.2 The view of the representative

The views of the representative play an important role in the decision whether or not to stop offering food and drink. In practice, the representative is usually one of the relatives (often partner or child). The representative acts as much as possible in the spirit and interest of the now incompetent person, taking the current situation as the guiding principle. She includes the opinions of the (other) relatives in her view.

The starting point is that the representative has knowledge of the patient's views and possible previous expressions, often partly based on the observations and opinions of (other) relatives. In a number of cases, the representative will have discussed this with the patient when the patient was still capable of giving her will. She may also have been involved in the drafting of an advance directive and/or discussions with the doctor on the subject. If the topic has never been discussed, the representative may have her own thoughts about what the patient would have wanted in the situation she is now in. The representative serves only the patient's interests and participates in decisions on behalf of the patient. However, the responsible healthcare provider is ultimately responsible.

The representative therefore plays an important role in interpreting the patient's behaviour and current wishes, interests and preferences and in interpreting a written or documented oral will.

6.6.3 Views of healthcare providers

The views of the caregivers involved also play an important role in the decision to stop offering food and drink or not. There is often a long-term and intensive involvement of professional caregivers (especially nurses) with the patient, which allows them to interpret the patient's expressions well. They may also have strong opinions about stopping offering food and drink.

6.6.4 Presence or absence of an advance directive or documented oral expressions of will

The question is whether, and to what extent, the previous written or documented oral expressions of will of the then still capable person are still valid for the current situation of an incompetent person with dementia. Past expressions of will may conflict with the current wishes, interests and preferences of the patient with dementia. For example, people with dementia may write down in an advance directive that they do not want to be offered food and drink in a situation of incompetency, while once in that situation they still take food and drink.

The general view of the KNMG is that the life of an incompetent patient with dementia is worthy of protection, regardless of what the patient has previously written about it (KNMG 2021). Whether or not the patient has (advanced) dementia does not add or detract from this. The actual wishes, interests and preferences of a patient with dementia therefore deserve to be respected. This is also stated in the UN Convention on Disability, which also applies to (legally incompetent) people with dementia.²⁴ This also applies in the case where the patient has stated in an advanced directive in the past that she does not want to receive food and drink if she has become incompetent in this regard. Because the need of the incompetent patient with dementia to be offered food and drink or not can no longer be tested by asking, decision-making regarding food and drink is based mainly on observations and interpretations of the patient's behaviour.

Thus, the presence of an advance directive or a documented oral expression of the patient's will plays a limited role in decision-making.

If there is no written or documented oral will, the offering of food and drink may be questioned by the representative or by the caregiver(s) involved. In that case, the patient's behaviour is leading (see below). It is then advisable to also consult one or more (uninvolved) colleagues in the decision-making process beforehand.

6.7 Decision-making

Stopping offering food and drink to an incompetent patient with dementia can be raised by the representative (preferably after consultation with the relatives) or by the professional caregiver(s) involved. A decision on this can only be made after a careful process.²⁵

In this situation, a balance must be struck between the patient's previous views and the current wishes and preferences of the patient with dementia (De Kort 2017). Components of the decision-making process may include consulting relevant experts, for example an elderly care physician, a clinical geriatrician or an internist in geriatrics, and/or holding a moral deliberation.

The decision partly depends on the actual situation at hand. The actual behaviour regarding eating and drinking (see section 7.4.2) is leading. The presence of an advance directive or a documented oral expression of will plays a limited role.

The responsible caregiver takes the decision to stop offering food and drink after consulting the representative and the other professional caregivers involved. In the home situation, the

²⁴ According to Article 12(4) UNCRPD, the basic principle is that the current wishes and expressions of will of the incompetent client are taken into account.

²⁵ Stopping the offering of food and drink in patients with dementia and the role of an advance directive in this regard are discussed in several English-language articles (Allen 2000, Christenson 2019, Dresser 2014, Fewing 2014, Kirk 2014, Marks 2020. Meier 2015, Meisel 2014, Menzel 2014 and 2017, Quil 2021, Tarzian 2019, Trowse 2019).

responsible care provider will almost always be the GP, in the nursing home the elderly care physician and in the hospital the medical specialist.

6.7.1 Decision-making in the presence of positive verbal and/or non-verbal cues regarding eating and drinking

It is not professionally justified to stop offering food and drink if the incompetent patient gives positive verbal and/or non-verbal cues regarding eating and drinking. This is independent of the existence of an advance directive or a documented verbal expression of will, and of the representative's opinion.

If the patient has indicated in a previous written advance directive or in a documented oral expression of will that she no longer wishes to be offered food and drink in the event of dementia, this statement will not be acted upon in this situation. This is because there is a discrepancy between the patient's current behaviour and the previously drafted directive. This discrepancy is a reason for continuing to offer food and drink. The committee sees this as an interpretation of the legal requirement of 'legitimate reasons' to deviate from a previously drafted written advance directive (see section 6.5.1).

Moreover, from the perspective of the caregivers involved, it is true that they cannot be expected/required on moral grounds to withhold food and drink from a person who gives positive verbal and non-verbal cues with regard to eating and drinking.

6.7.2 Decision-making in case of defensive behaviour

This section assumes a situation in which there is defensive behaviour, but with great difficulty the patient still manages to get food and drink down her throat. If this is no longer possible, force-feeding should be considered. In most cases, this will not be applied. Decisions on this are beyond the scope of this guideline.

If the patient exhibits consistent defensive behaviour for which treatment is not possible or effective, and if there is a written or documented oral will, food and drink are not offered. In this situation, there is no discrepancy between the patient's behaviour and the content of the advance directive or documented oral will. Permission from the representative to stop offering food and drink in this situation is desired, but not strictly necessary.

Even without a written or documented oral will, stopping the offering of food and drink can be professionally justified when a person consistently displays defensive behaviour. This requires consensus from the representative and the responsible caregiver.

It is conceivable that the defensive behaviour disappears when food and drink are no longer offered and that the patient then starts giving positive cues regarding food and drink. In that case, the decision not to offer food and drink is reconsidered.

6.7.3 Decision-making in the absence of both positive verbal and/or non-verbal cues regarding eating and drinking and defensive behaviour

In the situation where the patient does not give positive verbal or non-verbal cues with regard to eating and drinking, but also shows no defensive behaviour, she is completely dependent on the healthcare provider to eat and drink. In this situation, a decision to stop offering food and drink can be made in extreme cases, provided there is an advance directive or a documented verbal expression of will. The content of the advance directive or documented oral expression of will is particularly important here. What situation is described and

intended, and is that specific situation now being addressed? The responsible caregiver takes the decision to stop offering food and drink in consultation with the other professional caregivers involved and with the representative. This decision will always have to be multidisciplinary, based on patient-related considerations. If there is any doubt, the offering of food and drink will not be stopped.

Again, the decision to stop offering food and drink can be reconsidered if the patient starts giving positive cues with regard to eating and drinking.

If there is no advance directive or documented verbal expression of will and also no defensive behaviour, stopping offering food and drink in this situation is not professionally justified.

6.7.4 Decision-making and emotional strain on relatives and caregivers

Stopping offering food and drink can be emotionally draining for both relatives and professional caregivers. Offering food and drink is seen as a basic form of care. Both parties have often been involved in caring for the patient with dementia for a long time. In doing so, they may have strong feelings and opinions regarding the perspective of (not) offering food and drink. This requires good guidance and support for relatives and professional caregivers, both during the decision-making process and when implementing the decision to stop offering food and drink.

For healthcare providers, dealing with other treatment refusals (e.g. not starting antibiotics for pneumonia) may be easier to implement than not offering food and drink. In the latter situation, they can invoke conscientious objection (see section 4.11), provided they (have) transfer the care to others.

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Annex 1 Composition of committee and sounding board group

Committee

- Dr E. Bolt, general practitioner, researcher, on behalf of the Dutch College of General Practitioners (NHG)
- E.G. Burgering, MSc, general policy advisor Royal Dutch Medical Association (KNMG)
- Mr C. Compier, policy officer of the Dutch Society for a Voluntary End of Life (NVVE)
- Dr R. van Deijck, specialist in geriatrics, palliative care framework doctor, on behalf of the Society of Elderly Care Physicians (Verenso)
- Mr V. Derckx, health law adviser of the Royal Dutch Medical Association (KNMG)
- E. Dierink, nursing specialist, on behalf of the Dutch Nursing Society (V&VN)
- G. van Dijk, MA, ethics policy advisor Royal Dutch Medical Association (KNMG)
- Dr A. de Graeff, internist-oncologist, hospice physician, on behalf of the Dutch Internists Association (NIV), chairman committee
- Drs D. van Maare, general practitioner, palliative care framework physician, on behalf of the Dutch College of General Practitioners (NHG)
- Drs P. van Mierlo, clinical geriatrician, palliative care framework physician, on behalf of Netherlands Society of Clinical Geriatrics (NVKG)
- H. Speerstra, coordinator advisory centre of the Dutch Society for a Voluntary End of Life (NVVE) (until June 2022)
- N. Schrijver, nursing specialist, on behalf of the Dutch Nursing Society (V&VN) (from December 2022)
- S.E.M. Sommers, MSc, physician assistant, on behalf of the Dutch Association of Physician Assistants (NAPA) (until September 2022)
- K. Tol, nursing specialist, on behalf of the Dutch Nursing Society (V&VN) (until December 2022)
- Mr L. De Vito, lawyer of the Dutch Society for a Voluntary End of Life (NVVE)(from June 2022)
- H. van der Weerd, district nurse, on behalf of the Dutch Nursing Society (V&VN)

Sounding board group

- Dr S. Bekkers, cardiologist, on behalf of the Dutch Society of Cardiology (NVVC)
- L. Bisschops, chairman KBO Brabant, on behalf of the Catholic Association of the Elderly-Brabant (KBO-Brabant)
- G. Deleij, policy adviser on advocacy, on behalf of the Catholic Association of the Elderly/Protestant Christian Elderly Association (KBO-PCOB) (from May 2023)
- J. Gootjes, managing director, director, on behalf of the Dutch Association of Hospice Care (AHzN)
- M. van Oort, head of advocacy, on behalf of the Catholic Association of the Elderly/Protestant Christian Elderly Association (KBO-PCOB) (until May 2023)
- W. Toersen, senior advisor patient advocacy, on behalf of the Dutch Patient Federation
- J. van der Velden, general practitioner, consultant, trainer on behalf of the Dutch Centre of Expertise on Health Disparaties (Pharos)
- Prof K. Vissers, anaesthesiologist Pain Specialist & Palliative Care Consultant, Professor of Pain and Palliative Medicine, in a personal capacity
- E. Willemsen, policy officer, on behalf of the Catholic Association of the Elderly-Brabant (KBO-Brabant)

Annex 2 Literature review

1. Introduction

In order to obtain as complete an overview as possible of recent literature on voluntarily refraining from eating and drinking to hasten the end of life, it was decided to conduct a systematic literature review covering the period 2010-2021. This included all types of articles: empirical research, case reports, (systematic) reviews and contemplative articles. This chapter discusses the search strategy and the search results.

When writing the revised version of the guideline, the articles found during the literature search were used. No new (systematic) literature review was conducted for the period before 2010, but the references of the 2014 guide were used.

2. Search strategy

Search date: 7 & 10 January 2022

Databases: OVID Medline, PubMed, Embase, Cochrane Library

Search limits:

- Publication date: 2010-2022
 - -English, Dutch;
- Study type: no limit.

Search syntax:

MEDLINE (OVID) - 7 January 2022

- Euthanasia, Active, Voluntary/ (1798)
- Euthanasia, Passive/ (5984)
- Personal Autonomy/ (17902)
- Right to Die/ (4950)
- Suicide, Assisted/ (5995)
- Treatment Refusal/ (12057)
- Withholding Treatment/ (12517)
- Advance Directives/ (6360)
- or/1-8 (52363)
- 10 Fluid Therapy/ (21266)
- 11 Drinking/ (14593)
- 12 Eating/ (56617)
- 13 Feeding Methods/ (1230)
- 14 Dehydration/ (14016)
- 15 Fasting/ (37176)
- 16 Starvation/ (10070)
- 17 Feeding Behavior/ (89155)
- 18 or/10-17 (225142)
- 19 9 and 18 (579)
- 20 voluntar*.ti,ab. (66610)
- 21 refus*.ti,ab. (32392)
- 22 withhold*.ti,ab. (7499)
- 23 stopping.ti,ab. (19413)
- 24 cessat*.ti,ab. (71090)
- 25 eating.ti,ab. (72918)
- 26 drinking.ti,ab. (108551)
- 27 food*.ti,ab. (448477)
- 28 fluid*.ti,ab. (442152)
- 29 21 or 22 or 23 or 24 (128423)
- 30 25 or 26 or 27 or 28 (1026197)
- 31 20 and 29 and 30 (177)
- 32 19 or 31 (717)
- 33 VSED.ti,ab. (33)
- 34 32 or 33 (724)

PREMEDLINE (OVID) - 7 January 2022

- Euthanasia, Active, Voluntary/(3)
- Euthanasia, Passive/ (0)
- Personal Autonomy/ (6)
- Right to Die/(0)
- Suicide, Assisted/(8)
- Treatment Refusal/ (0)

- Withholding Treatment/ (12)
- Advance Directives/ (8) or/1-8 (34) 8
- 10 Fluid Therapy/ (11)
- 11 Drinking/ (4)
- 12 Eating/ (37) 13 Feeding Methods/ (1)
- 14 Dehydration/ (14)
- 15 Fasting/ (22) 16 Starvation/ (3)
- 17 Feeding Behavior/ (56)
- 18 or/10-17 (141)
- 19 9 and 18 (0) 20 voluntar*.ti,ab. (1289)
- 21 refus*.ti,ab. (514)
- 22 withhold*.ti,ab. (173)
- 23 stopping.ti,ab. (421) 24 cessat*.ti,ab. (1265)
- 25 eating.ti,ab. (1947)
- 26 drinking.ti,ab. (1709) 27 food*.ti,ab. (9825)
- 28 fluid*.ti,ab. (6232)
- 29 21 or 22 or 23 or 24 (2337)
- 30 25 or 26 or 27 or 28 (18653) 31 20 and 29 and 30 (2)
- 32 19 or 31 (2)
- 33 VSED.ti,ab. (0)
- 34 32 or 33 (2)

EMBASE (VIA EMBASE COM)) - 10 January 2022

#1	'voluntary euthanasia'/exp	1465
#2	'passive euthanasia'/exp	4913
#3	'personal autonomy'/exp	14482
#4	'right to die'/exp	4058
#5	'assisted suicide'/exp	5350
#6	'treatment refusal'/the	20727
#7	'treatment withdrawal'/the	21435
#8	'living will'/exp	9495
#9	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8	68628
#10	'fluid therapy'/exp	102807
#11	'drinking'/exp	26958
#12	'eating'/exp	39240
#13	'food intake'/the	135756
#14	'dehydration'/exp	46720
#15	'fasting'/the	15207
#16	'starvation'/exp	22168
#17	'food deprivation'/the	7394
#18	'feeding behaviour'/exp	194093
#19	#10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18	593957
#20	#9 AND #19	1426
#21	voluntar*:ti,ab	98974
#22	refus*:ti,ab OR withhold*:ti,ab OR stopping:ti,ab OR cessat*:ti,ab	211552
#23	eating:ti,ab OR drinking:ti,ab OR food*:ti,ab OR fluid*:ti,ab	1511729
#24	#21 AND #22 AND #23	269
#25	vsed:ti,ab	54

#26	#20 OR #24 OR #25	1669
#27	(#20 OR #24 OR #25) AND ([article]/lim OR [article in press]/lim OR [review]/lim) AND ([embase]/lim OR	887
	[pubmed-not-medline]/lim)	

COCHRANE LIBRARY (via wiley) - 10 JANUARY 2022

-	emante Emplant (via whey) 10 mile 111th 2022	
#1	MeSH descriptor: [Euthanasia, Active, Voluntary] explode all trees	3
#2	MeSH descriptor: [Euthanasia, Passive] 3 tree(s) exploded	2
#3	MeSH descriptor: [Personal Autonomy] explode all trees	228
#4	MeSH descriptor: [Right to Die] 1 tree(s) exploded	4
#5	MeSH descriptor: [Suicide, Assisted] 1 tree(s) exploded	0
#6	MeSH descriptor: [Treatment Refusal] this term only	271
#7	MeSH descriptor: [Withholding Treatment] this term only	429
#8	MeSH descriptor: [Advance Directives] 1 tree(s) exploded	121
#9	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8	1045
#10	MeSH descriptor: [Fluid Therapy] explode all trees	1775
#11	MeSH descriptor: [Drinking] 1 tree(s) exploded	599
#12	MeSH descriptor: [Eating] 1 tree(s) exploded	3837
#13	MeSH descriptor: [Feeding Methods] explode all trees	3565
#14	MeSH descriptor: [Dehydration] 1 tree(s) exploded	578
#15	MeSH descriptor: [Fasting] 1 tree(s) exploded	3385
#16	MeSH descriptor: [Starvation] explode all trees	49
#17	MeSH descriptor: [Feeding Behavior] this term only	3451
#18	#10 or #11 or #12 or #13 or #14 or #15 or #16 or #17	15350
#19	#9 and #18	20
#20	voluntar*:ti,ab	13267
#21	refus*:ti,ab	5383
#22	withhold*:ti,ab	892
#23	stopping:ti,ab	5725
#24	cessat*:ti,ab	16291
#25	eating:ti,ab	13204
#26	drinking:ti,ab	9664
#27	food*:ti,ab	43323
#28	fluid*:ti,ab	29501
#29	#21 or #22 or #23 or #24	27638
#30	#25 or #26 or #27 or #28	88580
#31	#20 and #29 and #30	37
#32	VSED:ti,ab	1
#33	#19 or #31 or #32 with Cochrane Library publication date Between Jan 2010 and Jan 2022	47

PUBMED - 10 January 2022

(((("euthanasia, active, voluntary"[MeSH Terms] OR "euthanasia, passive"[MeSH Terms] OR "personal autonomy"[MeSH Terms] OR "right to die"[MeSH Terms] OR "suicide, assisted"[MeSH Terms] OR "treatment refusal"[MeSH Terms] OR "withholding treatment"[MeSH Terms] OR "advance directives"[MeSH Terms]) AND ("fluid therapy"[MeSH Terms] OR "drinking"[MeSH Terms] OR "alcohol drinking"[MeSH Terms] OR "eating"[MeSH Terms] OR "feeding methods"[MeSH Terms] OR "dehydration"[MeSH Terms] OR "fasting"[MeSH Terms] OR "starvation"[MeSH Terms] OR "feeding behaviour"[MeSH Terms])) OR ("voluntar*"[Title/Abstract] AND ("refus*"[Title/Abstract] OR "withhold*"[Title/Abstract] OR "stopping"[Title/Abstract] OR "cessat*"[Title/Abstract]) AND ("eating"[Title/Abstract] OR "fluid*"[Title/Abstract]))) OR VSED[Title/Abstract]) AND 2010/01/01:2022/12/31[Date - Publication])

3. Search results

Table 3.1 shows the overall search results.

Table 3.1. Overall search results

Database	Number of hits
OVID Medline	724
OVID PreMedline	2
EMBASE.com	887
Cochrane Database of Systematic Reviews	3
CENTRAL	44

PubMed	492
Total number of hits	2152
N excluded (language, doubles, < 2010)	1080
Total number of unique hits	1072

1072 unique hits were screened by title and abstract. Of these, 905 were excluded as they were clearly not about VSTED.

Of the remaining 167 references, the full text was searched. Based on the full-text review, an additional 79 references were excluded.

3.1 References included

85 references were included:

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3.2 Excluded studies

Reference	Reason for exclusion
Atri, D., et al, Going from A to Z. New England Journal of Medicine, 2018. 378(1): p. 73-79.	Is not about VSED
Clinicians and the right to decide on withdrawal of treatment. Bmj, 2017. 356: p. j15.	Deals with stopping nutrition and moisture in vegetative state
Ackermann, R.J., Care of Patients at the End of Life: Advance Care Planning. Fp Essentials, 2016. 447: p. 25-31.	General narrative on ACP in dementia; only stopping artificial nutrition and fluid administration is discussed
Barilan, Y.M., The Role of Doctors in Hunger Strikes. Kennedy Institute of Ethics Journal, 2017. 27(3): p. 341-369.	Is about hunger strike of prisoners
Beldon, P., Conflict in care: Respecting the decision of the individual. Wounds UK, 2014. 10(1): p. 48-50.	Deals with cessation of tube feeding
Boulanger, A., et al, Opinions about the new law on end-of-life issues in a sample of french patients receiving palliative care. BMC Palliative Care, 2017. 16(1): p. 7.	Deals with refusal of artificial administration of nutrition and fluids
Brar, K., H.M. Mekala, and S. Lippmann, Dehydration in terminal illness: Which path forward? Journal of Family Practice, 2018. 67(10): p. E1-E3.	Deals with correction of dehydration in dying phase
Buck, H.G., Refusing artificial nutrition and hydration in advanced illness. Nursing, 2012. 42(9): p. 12-3.	Deals with refusal of artificial administration of nutrition and fluids
Bui, G.T., et al, Prevalence and contents of advance directives in patients receiving home parenteral nutrition. Journal of Parenteral and Enteral Nutrition, 2016. 40(3): p. 399-404.	Deals with patients receiving parenteral nutrition
Carlin, E., R. Dubash, and J. Kozlovski, End of life care in the emergency department. EMA - Emergency Medicine Australasia, 2020. 32(3): p. 504-506.	Deals with end-of-life care in emergency department
Chambaere, K., et al, Forgoing artificial nutrition or hydration at the end of life: a large cross-sectional survey in Belgium. Journal of Medical Ethics, 2014. 40(7): p. 501-4.	Deals with refraining from artificial administration of nutrition and fluids
Cheon, E., et al, Session 5: End-of-life feeding. Physiology and Behavior, 2020. 224.	Deals with nutrition in the terminal phase
Chuang, I.F., et al, Consistency in end-of-life care preferences between hospitalised elderly patients and their primary family caregivers. Patient Preference and Adherence, 2020. 14: p. 2377-2387.	Is not specifically about VSTED
Ciliberti, R., et al, The Italian law on informed consent and advance directives: new rules of conduct for the autonomy of doctors and patients in end-of-life care. Journal of Critical Care, 2018. 48: p. 178-182.	Is not specifically about VSTED
Colby, W.H., Nancy Cruzan and the Withhold Versus Withdraw Dilemma. Am J Bioeth, 2019. 19(3): p. 1-2.	Is about stopping tube feeding in dementia
Constable, C., Withdrawal of artificial nutrition and hydration for patients in a permanent vegetative state: changing tack. Bioethics, 2012. 26(3): p. 157-63.	Deals with stopping nutrition and moisture in vegetative state
Crozier, S., [Withholding and withdrawal of treatments at the acute phase of severe stroke: can we go until withdrawing artificial nutrition and hydration?]. Revue Neurologique, 2015. 171(2): p. 115-7.	Deals with stopping nutrition and hydration after CVA
Damghi, N., et al, Withholding and withdrawing life-sustaining therapy in a Moroccan Emergency Department: An observational study. BMC Emergency Medicine, 2011. 11.	Is about stopping treatment in ICU
Denys, K., B. Dannau, and N. Van Den Noortgate, Appropriate use of artificial nutrition and hydration near the end of life. Journal of Medicine, 2010. 66(9): p. 436-440.	Deals with refraining from artificial administration of nutrition and fluids at the end of life
Druml, C., et al, ESPEN guideline on ethical aspects of artificial nutrition and hydration. Clinical Nutrition, 2016. 35(3): p. 545-56.	Deals with ethical aspects of artificial nutrition and fluid administration
du Toit, J. and F. Miller, The Ethics of Continued Life-Sustaining Treatment for those Diagnosed as Braindead. Bioethics, 2016. 30(3): p. 151-8.	Is about life-sustaining treatment in brain death
Dyer, C., Leading campaigner for legalising assisted suicide dies of starvation. BMJ, 2014. 349: p. g7872.	Description of legal course of action at VSTED in MS
Evangelista, L.S., et al, Does the type and frequency of palliative care services received by patients with advanced heart failure impact symptom burden. Journal of Palliative Medicine, 2014. 17(1): p. 75-79.	Is not about VSTED
Friedrich, L., End-of-life nutrition: Is tube feeding the solution? Annals of Long-Term Care, 2013. 21(10): p. 30-33.	Deals with tube feeding in the terminal phase
Gent, M.J., et al, What influences attitudes towards clinically assisted hydration in the care of dying patients? A review of the literature. BMJ supportive & palliative care, 2015. 5(3): p. 223-31.	Only deals with moisture
Geppert, C.M.A., M.R. Andrews, and M.E. Druyan, Ethical issues in artificial nutrition and hydration: A review. Journal of Parenteral and Enteral Nutrition, 2010. 34(1): p. 79-88.	Deals with artificial administration of nutrition and fluids

Gustin, A.N. and R.A. Aslakson, Palliative Care for the Geriatric Anaesthesiologist. Anaesthesiology Clinics, 2015. 33(3): p. 591-605.	Deals with palliative care for anaesthesiologist in geriatric patients
Henry, B., Evolving ethical and legal implications for feeding at the end of life. Ann Palliat Med, 2017. 6(1): p. 87-90.	Is not specifically about VSTED
Ho, S. and L.K. Krishna, Artificial Hydration at the End of Life - Treating the Patient, Family or Physician? Annals of the Academy of Medicine, Singapore, 2015. 44(12): p. 558-60.	Deals with artificial administration of fluids
Holmes, S., Withholding or withdrawing nutrition at the end of life. Nursing Standard, 2010. 25(14): p. 43-6.	Deals with stopping nutrition and hydration after CVA
Hong, J.H., et al, Adopting advance directives reinforces patient participation in end-of-life care discussion. Cancer Research and Treatment, 2016. 48(2): p. 753-758.	Is not about VSTED
Hotopf, M., W. Lee, and A. Price, Assisted suicide: why psychiatrists should engage in the debate. British Journal of Psychiatry, 2011. 198(2): p. 83-84.	Is not specifically about VSTED
Hurford, J., The Briggsian Heresy? Should Previously Expressed Wishes Determine Best Interests in Decisions Relating to Withdrawal of Clinically-Assisted Nutrition and Hydration? The New Bioethics, 2020. 26(3): p. 238-252.	Deals with stopping feeding in comatose patients
Ikegami, N. and S. Ikezaki, Life sustaining treatment at end-of-life in Japan: Do the perspectives of the general public reflect those of the bereaved of patients who had died in hospitals? Health Policy, 2010. 98(2-3): p. 98-106.	Is not about VSTED
Irmak, N., Professional ethics in extreme circumstances: responsibilities of attending physicians and healthcare providers in hunger strikes. Theoretical Medicine & Bioethics, 2015. 36(4): p. 249-63.	Is about hunger strikers
Jakhar, J., S. Ambreen, and S. Prasad, Right to Life or Right to Die in Advanced Dementia: Physician-Assisted Dying. Frontiers in Psychiatry, 2020. 11.	Is not about VSTED
Jotkowitz, A., S. Glick, and A.Z. Zivotofsky, The case of Samuel Golubchuk and the right to live. Am J Bioeth, 2010. 10(3): p. 50-3.	Deals with cessation of treatment
Keam, B., et al, The attitudes of Korean cancer patients, family caregivers, oncologists, and members of the general public toward advance directives. Supportive Care in Cancer, 2013. 21(5): p. 1437-1444.	Concerns advance directives, not specifically with regards to VSTED
Kerr, C.W., et al, Clinical impact of a home-based palliative care programme: A hospice-private payer partnership. Journal of Pain and Symptom Management, 2014. 48(5): p. 883-892.e1.	Is not about VSTED
Kitzinger, C. and J. Kitzinger, Withdrawing artificial nutrition and hydration from minimally conscious and vegetative patients: family perspectives. J Med Ethics, 2015. 41(2): p. 157-60.	Deals with stopping artificial administration of nutrition and fluids
Kitzinger, C. and J. Kitzinger, Court applications for withdrawal of artificial nutrition and hydration from patients in a permanent vegetative state: family experiences. Journal of Medical Ethics, 2016. 42(1): p. 11-7.	Deals with stopping artificial administration of nutrition and fluids
Kitzinger, J. and C. Kitzinger, Deaths after feeding-tube withdrawal from patients in vegetative and minimally conscious states: A qualitative study of family experience. Palliat Med, 2018. 32(7): p. 1180-1188.	Deals with stopping artificial administration of nutrition and fluids
Klein Remane, U. and A. Fringer, [Voluntary Refusal of Food and Fluid in palliative care: a mapping literature review]. Pflege, 2013. 26(6): p. 411-20.	No full text
Kukla, R., Editorial Note. Kennedy Institute of Ethics Journal, 2017. 27(3): p. vii-ix.	Is not about VSTED
Lantos, J.D., What we talk about when we talk about ethics. Hastings Center Report, 2014. 44(1 Suppl): p. S40-4.	Is about newborn
Malia, C. and M.I. Bennett, What influences patients' decisions on artificial hydration at the end of life? A Q-methodology study. Journal of Pain & Symptom Management, 2011. 42(2): p. 192-201.	Deals with artificial administration of nutrition and fluids at the end of life
Manu, E.R., et al, Advance Directives and Care Received by Older Nursing Home Residents. Am J Hosp Palliat Care, 2017. 34(2): p. 105-110.	Is not about VSTED
Mazzola, R., S. Görres, and N. Schmacke, [Proxy decision about long-term gastrostomy tubes (PEG catheters) in patients with dementia in long-term nursing care: reducing decision uncertainty in health-related taboo topics]. Pflege, 2015. 28(6): p. 347.	Deals with decisions made by relatives about PEG catheters in dementia
Moratti, S., The Englaro Case: withdrawal of treatment from a patient in a permanent vegetative state in Italy. Camb Q Healthc Ethics, 2010. 19(3): p. 372-80.	Deals with stopping artificial feeding in vegetative state
Moreschi, C., et al, The Eluana Englaro Case: cause of death after the withdrawal of artificial nutrition and hydration in a subject in a permanent vegetative state and with quadriplegia. Forensic Science International, 2013. 231(1-3): p. e24-9.	Deals with stopping artificial feeding in vegetative state
Nau, J.Y., [A French hospital condemned to resume nutritional support]. Revue Medicale Suisse, 2013. 9(388): p. 1174-5.	Deals with resumption of artificial nutrition and fluid administration
Phua, J., et al, Withholding and withdrawal of life-sustaining treatments in intensive care Units in Asia. JAMA Internal Medicine, 2015. 175(3): p. 363-372.	Is not about VSTED
Pilkington, B.C., On omissions and artificial hydration and nutrition. Journal of Medicine & Philosophy, 2014. 39(4): p. 430-43.	Deals with artificial administration of nutrition and fluids
Porter, K., et al, Supporting people who have eating and drinking difficulties. Clinical Medicine, Journal of	Is not about VSTED
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Rabinowich, A., et al, Withholding Treatment From the Dying Patient: The Influence of Medical School on Students' Attitudes. J Bioeth Inq, 2019. 16(2): p. 217-225.	Deals with stopping artificial administration of nutrition and fluids
Rady, M.Y. and J.L. Verheijde, Judicial oversight of life-ending withdrawal of assisted nutrition and hydration in disorders of consciousness in the United Kingdom: A matter of life and death. Med Leg J, 2017. 85(3): p. 148-154.	Deals with discontinuation of nutrition and fluids in reduced consciousness
Raijmakers, N.J., et al, Variation in attitudes towards artificial hydration at the end of life: a systematic literature review. Current Opinion in Supportive & Palliative Care, 2011. 5(3): p. 265-72.	Is about moisture
Richards, B. and J. Coggon, Assisted Dying in Australia and Limiting Court Involvement in Withdrawal of Nutrition and Hydration. Journal of Bioethical Inquiry, 2018. 15(1): p. 15-18.	Deals with cessation of artificial nutrition and fluids
Rodgers, J.J. and J.S. Kass, Assessment of Medical Decision-making Capacity in Patients with Dementia. CONTINUUM Lifelong Learning in Neurology, 2018. 24(3, BEHAVIORAL NEUROLOGY AND PSYCHIATRY): p. 920-925.	Deals with determining willpower in dementia
Schwartz, D.B., et al, Ethical Aspects of Artificially Administered Nutrition and Hydration: An ASPEN Position Paper. Nutr Clin Pract, 2021. 36(2): p. 254-267.	Is not about VSTED
Sciubba, J.J., End-of-life care in the head and neck cancer patient. Oral Diseases, 2016. 22(8): p. 740-744.	Is not about VSTED
Seol, E.M., C.K. Koh, and E.K. Kim, Critical Care Nurses' Perceptions of Parenteral and Enteral Nutrition at the End-of-Life in South Korea. J Palliat Care, 2020. 35(2): p. 110-115.	Deals with artificial administration of nutrition and fluids
Sharma, R., et al, Management of hunger strike: A medical, ethical and legal conundrum. Medico-Legal Journal, 2020. 88(4): p. 215-219.	Is about hunger strike
Shaulov, A., et al, Preparedness for End of Life-a Survey of Jerusalem District Nursing Homes. J Am Geriatr Soc, 2015. 63(10): p. 2114-9.	Is not about VSTED
Shreves, A. and E. Marcolini, End of life/palliative care/ethics. Emergency Medicine Clinics of North America, 2014. 32(4): p. 955-974.	Is not about VSTED
Somers, E., C. Grey, and V. Satkoske, Withholding versus withdrawing treatment: artificial nutrition and hydration as a model. Current Opinion in Supportive & Palliative Care, 2016. 10(3): p. 208-13.	Deals with artificial administration of nutrition and fluids
Stiefelhagen, P., [Difficult decisions regarding patients with dementia]. MMW Fortschr Med, 2016. 158(5): p. 10-1.	Is not about VSTED
Tannier, C., et al, [Withdrawal of artificial nutrition and hydration in severe stroke: medical, legal and ethical considerations]. Revue Neurologique, 2015. 171(2): p. 166-72.	Is about stopping artificial nutrition and fluids in CVA
Thorns, A., Ethical and legal issues in end-of-life care. Clinical Medicine, 2010. 10(3): p. 282-5.	Is not about VSTED
Tolle, S.W., V.M. Jimenez, and E. Eckstrom, It is Time to Remove Feeding Tubes From POLST Forms. J Am Geriatr Soc, 2019. 67(3): p. 626-628.	Is not about VSTED
Tschirhart, E.C., Q. Du, and A.S. Kelley, Factors Influencing the Use of Intensive Procedures at the End of Life. Journal of the American Geriatrics Society, 2014. 62(11): p. 2088-2094.	Is not about VSTED
van den Hondel, K., et al, [Forensic implications of humane self-chosen death in the Netherlands]. Dutch Journal of Medicine, 2020. 164(06): p. 17.	Is not about VSTED
Volicer, L. and J. Simard, Palliative care and quality of life for people with dementia: Medical and psychosocial interventions. International Psychogeriatrics, 2015. 27(10): p. 1623-1634.	Is not about VSTED
Wade, D.T., Clinically assisted nutrition and hydration. BMJ, 2018. 362: p. k3869.	Deals with stopping artificial feeding in cases of lowered consciousness/willingness
Wagemans, A., et al, End-of-life decisions: An important theme in the care for people with intellectual disabilities. Journal of Intellectual Disability Research, 2010. 54(6): p. 516-524.	Is not about VSTED
Weber, M., [Between self determination and nursing care. Force feeding of patients]. Pflege Z, 2011. 64(12): p. 750-2.	Deals with forced feeding
Weimann, A., [Ethical issues of artificial nutritional support]. Ther Umsch, 2014. 71(3): p. 177-83.	Deals with artificial administration of nutrition and fluids
Werner, S., ["We cannot allow anyone to starve". Nourishment and fluids at the end of life]. Pflege Zeitschrift, 2013. 66(1): p. 30-3.	No full text