

GUIDE

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

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Nederlandse Vereniging
voor Klinische Geriatrie



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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 deliberately stopped eating and drinking to hasten death. This sometimes involved people with a death wish who requested euthanasia

rejected, but also to people who had principled or emotional objections to euthanasia, or did not want to burden the doctor with this. Others felt that it was their own responsibility to achieve a self-chosen end of life.

These data, social developments (such as increased attention to the self-chosen end of life) and reports from doctors' workplaces were the reason for the Royal Dutch Society for the Promotion of Medicine (KNMG) to set up a committee in 2013. The committee was tasked with 'drawing up a guideline that enables doctors, nurses and caregivers to properly prepare and guide patients, and to provide or continue adequate palliative care if patients have made the choice to to consciously refrain from eating and drinking to hasten the end of life'.

In 2014, the KNMG published the guide Care for people who consciously refrain from eating and drinking to hasten the end of life. The boards of the Dutch Society of General Practitioners (NHG) and the Association of Specialists in Geriatric Medicine (Verenso) approved the guideline. The Dutch Association for Clinical Geriatrics (NVKG) and Nurses and Caregivers in the Netherlands (V&VN) authorized the guideline.

1.2 Revision of the guidance

In 2021, the KNMG decided to revise the guide after a needs survey in the agenda committee of the KNMG/IKNL1. 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 Association of General Practitioners (NHG), the Dutch Association of Internists (NIV), the Dutch Association for Clinical Geriatrics (NVKG), the Dutch Association for Voluntary End of Life (NVVE), Nurses & Caregivers Netherlands (V&VN), the Association of Geriatric Medicine Specialists (Verenso) and the KNMG.

A sounding board group was also put together with representatives of the Dutch Hospice Care Association (AHzN), the Catholic Association of the Elderly-Brabant (KBO-Brabant), the Catholic Association of the Elderly/Protestant Christian Association for the Elderly (KBO-PCOB), the Dutch Association for Cardiology (NVVC), the Patient Federation of the Netherlands, the national expertise center Pharos and (in a personal capacity) Prof. Dr. KCO Visser, anesthesiologist and professor of Pain and Palliative Medicine (Radboud university medical center).

1.3 Committee working method and accountability

The committee met five times between April 2022 and March 2023. In addition, a systematic literature review was conducted by a literature researcher to obtain the most complete possible overview of recent literature on consciously stopping eating and drinking to hasten the end of life (see Appendix 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 The Netherlands.

The relevant literature was examined and draft texts were prepared. The draft texts were submitted to the sounding board group for comment twice, in August 2022 and October 2022. The committee has assessed all draft texts, adjusted and adopted them if necessary. The draft guidance was then submitted to the members of the sounding board group in May 2023 and at the same time offered for comment to the professional and scientific associations of the committee members. The committee then assessed and processed all comments. Commenters received feedback prior to authorization.

The content of the guide was adopted on October 10, 2023. The guide was subsequently sent to the professional and scientific associations of the committee members for authorization/approval/consent.

The guidance was approved/authorized/agreed to on December 5, 2023. Finally, the KNMG federation board has revised guidelines adopted on December 14, 2023.

1.4 Target group and meaning of the guide

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

The guide can also be read and used by other healthcare providers, volunteers, patients and loved ones. However, the choice of words and terminology are not tailored to this. Relatives can find information in the book 'Uitweg' to guide and care for the patient as best as possible during the process of consciously stopping eating and drinking (Chabot 2022).

Furthermore, the [brochure 'Consciously stop eating and drinking'](#) from the NVVE (2022) are used, as well as the [podcast with a conversation with Eva Bolt](#).

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

1.5 Changes compared to the 2014 guideline

The following substantive changes have been made compared to the 2014 guidance:

- The committee has changed the title of the guide to 'Care for people who stop eating and drinking to hasten the end of life'. • The guide is divided into three parts:
 1. General information
 2. Provide people who consciously stop eating and drinking to hasten the end of life.
 3. Stop offering food and drinks if they wish to do so. incapacitated patients with dementia
- The abbreviation BSTED is used for 'consciously stopping eating and drinking' used.
- Chapter 1 describes the history of the guide and the course of events after the publication of the previous version of the guide. Nursing specialists and physician assistants have been added to the target group. Two recently published guidelines on BSTED are also briefly described.
- Chapter 2 argues why the title of the manual scope has changed. Furthermore, attention is paid to offering food and drink versus artificial administration of food and fluid, to refraining from treatment (both relevant for Chapter 7) and to proactive care planning.
- The literature has been updated based on the systematic literature review (see appendix 2). The empirical data in Chapter 3 has been updated accordingly. For Chapter 3, a summary has been added to the beginning of the chapter.

- Chapter 4 discusses the legal and ethical background of BSTED is elaborated in more detail and the relationship between BSTED and suicide is discussed in more depth. 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. Proactive care planning and offering food and drink versus administering nutrition and fluid are also discussed.
- Chapter 5 explicitly discusses decision-making. There is a summary added to the beginning of the chapter. BSTED is no longer recommended for patients younger than 60 years of age, because several cases have been described showing that people younger than 60 years of age can also end their lives by stopping eating and drinking. Furthermore, the content of Chapter 5 has only been adjusted in detail.
- Case studies have been added (chapter 6).
- Chapter 7 (Stopping offering food and drinks to incapacitated patients) has been completely rewritten compared to the corresponding chapter in the previous guide. It is tailored to people with dementia. Situations in which there is no defensive behavior are also discussed. The argumentation as to when and when not to offer food and drinks has been elaborated in more detail. A summary has been added to the beginning of the chapter.

1.6 Reading guide

Chapter 2 contains a description of the relevant features and concepts in this guide. Chapter 3 focuses on empirical data. Chapter 4 discusses proactive care planning and legal and ethical aspects are further elaborated. Chapter 5 describes the decision-making, guidance and care by professionals, volunteers and relatives of patients who consciously stop eating and drinking.

Chapter 6 contains experiences of patients, relatives and professionals with situations in which a patient has consciously stopped eating and drinking to hasten the end of life. Chapter 7 describes how to deal with stopping offering food and drinks to incapacitated patients with dementia. Summaries have been added to the (extensive) chapters 3, 4, 5 and 7 at the beginning of the chapter.

The committee has chosen to speak of 'she' and 'her' where the gender of a patient, loved one or care provider is not clear. Where 'she' or 'her' is stated, 'he', 'who', 'them' or 'his', 'his', 'their' can also be read.

1.7 Other guidelines BSTED

An American guideline on BSTED was published in 2023 (Wechkin 2023). The authors indicate in their article that this guideline is partly based on the 2014 KNMG guideline, but has been adapted to the American situation, especially with regard to legislation, organization of healthcare and attitude towards end-of-life care. .

Gruenewald (2018) provides practical suggestions and a checklist for healthcare providers and nursing home staff in the United States who deal with patients who want to choose BSTED.

The advice in the above guidelines is not essentially different from that in the current guide. The focus of the American guideline is on patients with a life-threatening illness with a prognosis of months to several years. The guideline considers death after BSTED as a natural death. Stopping offering food and drinks to incapacitated patients falls outside the scope of both guidelines. The committee is not aware of other guidelines with regard to BSTED, nor of guidelines with regard to stopping offering food and drinks to incapacitated patients with dementia.

2. CHARACTERISTICS AND DEFINITION

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

2.1 Patients

This guideline concerns, on the one hand, people who do not have a classifiable disease and, on the other hand, patients who are in a condition that a doctor regards as a disease or combination of diseases and complaints.

notes. People who do not have a classifiable disease, but at some point involve the doctor, physician assistant, nurse specialist, nurse and/or caregiver in (the intention to) consciously stop eating and drinking to hasten the end of life, then become 'patients'.¹ in the context of the treatment agreement as described in the Medical Treatment Agreement Act (WGBO).^{2,3} This guide also speaks about patients.

2.2 Consciously stop eating and drinking to end life speed up

The description 'consciously stopping eating and drinking to hasten the end of life' refers to the decision that someone makes to stop eating and drinking with the aim of hastening the end of life. This also includes consciously refusing food and drink that is offered and consciously refusing artificial administration of food and fluid. In the literature, this is defined as 'the act of a competent person who voluntarily and deliberately decides to stop eating and drinking with the primary purpose of hastening death due to persistent unacceptable suffering' (Ivanovic 2014). The difference with a hunger strike is that the intention is not to die.

In English-language literature, the term 'voluntar(ily) stopping eating and drinking' is mainly used (Gruenewald 2018, Ivanovic 2014, Lowers 2021-1, Quill 2018-1, Quill 2022). The abbreviation 'VSED' is also used for this

gehanteerd. Andere gebruikte termen zijn '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) en 'patients refusal of hydration and nutrition' (Bernat 1993).

This terminology is strongly based on the literature, culture and case law in the United States. In German-language literature from Germany, Switzerland and Austria, 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) are used.

The committee maintains the 2014 committee's choice to include 'conscious' in the description, because this expresses that it is a choice that the person himself and consciously makes. For this reason, the committee does not use terms such as 'voluntary', 'refuse' or 'abstain'. The committee also does not use the term 'mortification', because very different meanings are attributed to it.

The committee has chosen to replace the term 'renounce' in the title of the guide with 'stop'. This is more in line with the usage in practice and the terminology in international literature. Where an abbreviation is used, BSTED (Consciously Stop Eating and Drinking) has been chosen.

² See art. 7:446 paragraph 1 of the Dutch Civil Code (BW), part of the Medical Treatment Agreement Act (WGBO).

³ Depending on the situation and the nature of the decisions, treatment decisions can also be made independently by physician assistants or nursing specialists listen.

BSTED is fundamentally different from gradually reducing food and drink intake as part of a terminal disease process or as a result of old age, because in those situations it is not an active choice of the patient.

In the remainder of this guide, for the sake of readability, the addition 'to hasten the end of life' will be omitted.

2.3 Stop offering food and drinks to incapacitated patients⁴

It is conceivable that the responsible healthcare provider decides to stop offering food and fluid to an incapacitated patient on the basis of an advance directive, documented previous oral expressions of intent by the patient or the opinion of the representative and the healthcare provider(s) involved. of the patient. This mainly concerns patients with dementia. See also Chapter 4 and Chapter 7. In such cases, at the time of the decision to stop offering food and drinks, there is no **conscious** cessation of eating and drinking by the patient himself.

A patient must be considered competent until the contrary has been established (KNMG 2004, p. 92). Decisional capacity can fluctuate over time and can vary per decision-making or action domain. The following aspects are characteristic of a patient who is competent to make a particular decision:

1. making a choice known;
2. understanding relevant information;
3. realize and appreciate the significance of the information for the own situation;
4. logical reasoning and considering the information of the treatment options.

In these aspects, the patient's cognitive skills are in the foreground. The [guideline on decision-making skills and decision-making capacity](#):

[supporting and assessing the Long-term Quality Impulse Foundation Concern](#) (SKILZ) advocates taking the patient's emotions and values into account when determining legal capacity. The guideline uses ten criteria for decisional capacity: 1) understand information, 2) gain insight into one's own situation, 3) look for options for action, 4) consider options for action, 5) assess the consequences of preferred option(s) for oneself, 6) consequences of preferred option (s) assess for others, 7) motivate choice in an empathetic and understandable way, 8) motivate choice based on goals and values, 9) be free from coercive influences from within, and 10) be free from coercive influences from outside.

Competent patients are patients who 'cannot be considered capable of a reasonable assessment of their interests with regard to a decision or situation at hand' (KNMG 2004, p. 91). Wilsonian competence refers to a patient's decision-making skills depending on the choices or decisions made in a certain context. A step-by-step plan has been developed for testing competence (see KNMG 2004). The SKILZ decision-making skills and decision-making guide also provides a step-by-step plan.

2.4 Offering food and drinks versus artificial administration of food and moisture

Relatives and/or caregivers⁵ can play a role in the patient's eating and drinking. A distinction must be made between:

⁴ Sometimes the term 'incompetence of judgment and decision' is used. In legal

literature only talks about incapacity. This term will be used further in this guide. Wilson always implies competence incapacity of judgement.

⁵ In this guide, the committee uses the term healthcare provider(s) as a collective term for doctors, physician assistants, nursing specialists, nurses and caregivers.

- providing or placing food and fluid;
- helping patients eat and drink if they cannot do so themselves for physical or cognitive reasons;
- the artificial administration of nutrition and/or fluid through a nasal passage gastric tube, PEG or PRG catheter or by subcutaneous (fluid only) or intravenous route. This is reserved for authorized healthcare providers. The decision to start artificial administration of food and/or fluid is made by the doctor. Discontinuing artificial nutrition and/or fluids may be a decision by the doctor, but can also be based on the patient's wishes. Nurses and caregivers can play a role in administering nutrition and fluid through a tube or IV, provided they are authorized and competent to do so under the Individual Healthcare Professions Act (BIG Act). This also applies to the insertion or removal by a nurse of the tube or IV that is necessary for this.

2.5 Withholding treatment

Patients always have the right to opt out of (specific aspects of) treatment, nursing and care. They are entitled (under the WGBO) to clear information from the doctor about her medical condition, prognosis and treatment options in order to make an informed decision. Based on this information, patients may or may not give healthcare providers permission to treat, nurse or provide 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 loved ones who are dealing with a life-threatening condition or vulnerability, by preventing and relieving suffering, through early detection 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

vulnerability, palliative care focuses on maintaining autonomy, access to information and options (IKNL/Palliatie 2017, p. 9).

Because consistently stopping eating and drinking inevitably leads to death, the committee considers the care of the person who makes this decision to be a form of palliative care, even if there is no direct cause of action at the time the decision is made. life-threatening disease.

2.7 Proactive care planning

Proactive care planning (advance care planning, ACP) enables competent people to identify values that are important to them, to think about the meaning and consequences of a possible serious illness, and to formulate goals and preferences for future medical treatments and care, and discuss these with loved ones and healthcare providers (see the [Proactive Care Planning Guideline](#)) (KNMG 2021-3, Rietjens 2017). 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 incapacitated (see section 2.3). In this way, someone's preferences can be taken into account when they are unable to make decisions themselves.

Proactive care planning is discussed in Chapter 4, with special attention to advance directives and previous oral expressions of intent regarding stopping eating and drinking.

2.8 Palliative sedation

Palliative sedation is 'the intentional lowering of a patient's level of consciousness in the final phase of life with the aim of relieving suffering' ([Palliative Sedation Guideline](#)). The goal of palliative sedation is to relieve the patient's suffering by reducing consciousness.

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

2.9 Division of responsibility and directing treatment

In any care process, it is essential that the responsibilities of the various care providers are clearly divided and assigned. If necessary, it is explicitly agreed and described who is responsible for what. Preferably, it also describes how decisions are made and what the escalation procedure is, 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 healthcare providers involved a decisive vote or to have the decision taken at another (higher) level.

Palliative care can involve so many different healthcare providers and disciplines that it may be necessary to designate one healthcare provider who takes the lead, the so-called coordinating practitioner ([Guideline Division of responsibility in collaboration in healthcare](#)). However, a coordinating practitioner only needs to be appointed if the number of healthcare providers involved and the complexity of the care make this necessary.

The coordinating practitioner ensures in any case that:

- the continuity and coherence of care provided to the patient are monitored and that treatment adjustments are initiated where necessary;
- there is adequate information exchange 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 to answer questions about the treatment in a timely manner. The coordinating practitioner does not have to be the point of contact and be able to answer all questions, but must be able to refer to someone who can provide those answers.

The coordinating practitioner is usually a BIG-registered healthcare provider, but that is not necessarily the case. She must have the required competence for the tasks of the coordinating practitioner, as described above.

focused on the relevant palliative care. A coordinating practitioner is not necessarily always a doctor. Depending on the circumstances and the healthcare sector, a healthcare provider from another professional group, for example a healthcare psychologist, a physician assistant, a nurse specialist or a nurse or other healthcare provider, can also fulfill the role of coordinating practitioner.

The basic principle is that every healthcare provider involved in the treatment of a patient has and holds their own professional responsibility towards that patient. It is important that the patient is informed about who the coordinating practitioner is and - if someone else - who the point of contact is. It depends on the situation which healthcare provider makes the decisions. If a coordinating practitioner has been appointed, this does not necessarily have to be the one who makes the decisions.

This guide also refers to the 'responsible healthcare provider'. In the home situation this will often be the general practitioner, in the nursing home the geriatric specialist and in the hospital the medical specialist.

3. EMPIRICAL DATA ON BSTED

3.1 Summary

- BSTED to hasten the end of life plays a role in 0.5-1.7% of all deaths in the Netherlands.
- It concerns more women than men. Many patients are older than 80 years.
- In approximately 60% of cases there is a serious physical illness and in 12-30% of (incipient) dementia. In approximately 25% of cases there is no serious physical or psychiatric condition, but there is an accumulation of old age complaints and/or 'completed life' problems.
- Many considerations play a role in the decision to quit eating and drinking: mainly physical complaints (particularly fatigue

and pain), suffering from life, completed life, having no purpose in life, dependence, disability and loss of dignity.

- In 19-45% of cases, a euthanasia request is rejected or not carried out. •

Qualitative research from the

Netherlands suggests that there is regular

the decision to stop eating and drinking is revisited. Retrospective data from American research suggests that 13% of patients reconsider this decision.

- Most patients die within 1-3 weeks. If patients continue to drink, the process takes longer.
- The course of the patient's complaints and burden has not been systematically mapped out. Global retrospective assessments of caregivers and case reports indicate a dying process that usually involves relatively few symptoms and little suffering, if appropriate care is in place.
- After stopping eating, the feeling of hunger disappears after a few days, provided that no carbohydrates are consumed.
- Good oral care is essential to reduce the feeling of thirst or dryness mouth as much as possible.
- A Dutch study shows this during BSTED palliative sedation is used in 28% of cases.
- BSTED can be a major burden for relatives/informal caregivers, because they may feel that they have to defend the patient's choice in relation to the environment, feel responsible for a good course and at the same time may have great difficulty with the decision of their neighbor. They often seem to experience insufficient support from professional caregivers.
- There appear to be inter-individual and international differences in the attitude of healthcare providers towards stopping eating and drinking. Most healthcare providers experience no moral objections. Care for patients who stop eating and drinking is sometimes experienced as 'passive euthanasia' (withholding a life-prolonging action) or assisted suicide. Care sometimes becomes difficult and

experience 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 if they had a death wish.

- In order to properly guide a patient in decision-making, preparation and possible implementation of BSTED, 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 consciously stopping eating and drinking. These are descriptive studies (Bolt 2015-1 and 2015-26, 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 studies (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, Ter-man 2001, Webster 2016).

3.3 Pathophysiological and clinical consequences of stopping eating and drinking

The body obtains energy primarily from the combustion of carbohydrates and fats. Under normal circumstances, glucose is the most important fuel for most cells. During strict fasting occurs in the first 24 hours

⁶ Bolt 2015-1 and Bolt 2015-2 refer to the same study. In the following, reference will only be made to Bolt 2015-1.

glucose is released from the liver by the breakdown of glycogen (glycogenolysis) (Kerndt 1982, Owen 1983). However, this source is quickly exhausted. Then the most important energy sources are:

- formation of glucose in the liver through the 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 are also broken down in the muscles and in the liver to maintain the glucose level in the blood and thus the energy supply to the brain.

When the protein reserves of the muscles are used, increasing weakness occurs.

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

1. Fat burning produces ketone bodies, which lead 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 produces during strict fasting. This may also result in a decrease in pain complaints.
3. Over time, low fluid intake leads to increasing dehydration and progressive renal dysfunction, which are accompanied by drowsiness. This drowsiness is often experienced as pleasant.

The feeling of hunger disappears after a few days, provided no carbohydrates (for example in soft drinks or fruit) are consumed (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 continued to drink, but it is not known how much fluid they consumed. The median age was 27 years (range 18-49). The most common complaints were pain

chest (23%), abdominal pain (22%), flank pain (20%), weakness (20%) and dizziness (20%). 62.5% had bradycardia and 32% had hypothermia. Laboratory examination revealed a (usually mild) leukopenia in 62% of cases, a (usually mild) thrombopenia in 58%, anemia in 18% and a prolonged INR in 41%.

Bradycardia has also been described during starvation 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 consciously stops eating and drinking, other factors also play a role. In the context of the disease, the so-called anorexia-cachexia syndrome may occur to a greater or lesser extent (depending on the nature of the disease and life expectancy) ([Guideline Anorexia and weight loss](#)). This is characterized by the combination of anorexia (often accompanied by a feeling of rapid satiety), loss of muscle mass, weakness and cachexia (extreme emaciation). An increased production of inflammatory mediators (cytokines) plays a role in this. Typically (in contrast to the situation with fasting) the loss of muscle mass and protein occurs at an early stage.

Only two studies have been published on the effect of discontinuing fluid intake in healthy individuals (Phillips 1984, Terman 2006). In the first study, seven healthy older men (average age 70) were compared 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 turned out that, compared to young people, elderly people suffered much less from thirst (despite a greater increase in serum sodium) and dry mouth and that elderly people were much less likely to replenish the fluid deficit after 24 hours. An explanation for this could be that there is a higher threshold for thirst sensations in the elderly

consists. 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 approximately 40 ml per day (Terman 2006). He experienced little hunger, but did experience unpleasant thirst (graded as five on a scale of zero to ten). The thirst was manageable thanks to good oral care.

He described a not unpleasant drowsiness after a few days he attributed to the ketone bodies produced.

No further literature has been found on the clinical consequences of consciously stopping drinking. It is often assumed that increased serum sodium leads to thirst. Research in terminally ill patients (who would live another 2-35 days) who no longer drink during the dying process shows that serum sodium is usually normal (Vullo-Navich 1998). The patients with an elevated serum sodium indicated slightly more discomfort than the patients with a normal serum sodium, but the difference was small. In these terminally ill patients, there was no difference in the patient's perceived (dis)comfort between patients who drank less than 500 ml per day and patients who drank more. It is not known to what extent these data apply to patients with a longer life expectancy.

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

After consciously stopping drinking, urine production eventually drops to a minimal level, the amount of stool decreases, mucus secretion from the respiratory tract decreases and ultimately consciousness decreases. The direct causes of death mentioned are: heart damage, arrhythmia

niches due to hypokalaemia, pneumonia and sepsis (Sullivan 1993).

3.4 Epidemiological data

In 1997, a publication was published on the frequency of withholding (artificial) administration of food and fluid at the end of life in the Netherlands (Van der Heide 1997). In 8% of all deaths, death appeared to follow a decision to stop fluids and nutrition. However, three quarters of these cases involved partially or completely incapacitated patients. The percentage found (8%) is therefore not a correct estimate of the number of deaths in which the patient **consciously** stopped eating and drinking.

Ganzini conducted a study among 307 nurses in Oregon, United States (Ganzini 2003). 102 respondents indicated that in the previous four years they had cared for a patient in hospice who consciously 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 consciously stopping eating and drinking was published for the first time (Chabot 2007; see also Chabot 2009). From a national sample, confidants of deceased persons (n=97) who had been involved in BSTED were traced. See table 3.1 for specific patient characteristics. Based on this sample, it was estimated that in the period 1999-2003, 2800 people per year (2.1% of all deaths) in the Netherlands had died as a result of BSTED.

The reasons for the decision to stop eating and drinking fell into four groups during factor analysis:

1. somatic reasons (pain, shortness of breath, nausea/vomiting and general weakness/fatigue);
2. dependence (disability due to difficulty walking, blindness or deafness, inability to care for oneself, incontinence or the fear of

- for, being a burden to others or fear thereof and/or loss of dignity or humiliation);
3. demoralization (gloom, loneliness and/or perceived meaninglessness of life);
 4. control over time and place of death (the desire to die control, the desire to die at home and/or to be done with life).

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

In the Death Surveys of 2010 (Van der Heide 2012-1, Onwuteaka 2012) and 2015 (Hagens 2021), a lower estimate was made of the number of people who died as a result of consciously 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, Chabot's research and the Death Surveys are not easily comparable with each other, because the information came from different types of respondents (Chabot confidants and Van der Heide doctors). The Death Surveys may lead to an underestimate of the frequency with which BSTED occurs, partly because these studies only included cases of cessation of eating and drinking in which a doctor was aware. On the other hand, the frequency estimate in Chabot's study may have been slightly too high. This is because the confidential counselors in that study sometimes wrongly interpreted stopping eating and drinking as a conscious intention to hasten the end of life. As a result, his frequency estimate may have been slightly too high. After correction for [this⁷](#), the estimates in Chabot's research are still four times higher than those in the Deaths report.

⁷ Personal communication Boudewijn Chabot, May 2013.

studies (1.7%, 0.4% and 0.5% respectively).

In the practical study (part of the second evaluation of the Termination of Life on Request and Assisted Suicide Act, in short: the Euthanasia Act), 45% of general practitioners, 57% of geriatric medicine specialists and 42% of medical specialists had sometimes treated a patient. treatment that deliberately ended his life by stopping eating and drinking (Van der Heide 2012-2 and Bolt 2015-1). Bolt conducted a survey among a random sample of 1100 general practitioners (Bolt 2015-1). The response rate was 72%. Of the 708 respondents, 46% had treated a patient who died as a result of BSTED; for 9% this had been in the past year.

A more extensive questionnaire was completed by 285 general practitioners. Patients who had started eating and drinking again, or who had advanced dementia, were excluded from the study. The patient data of the obtained cases (n=99) are listed in table 3.1. The estimated life expectancy was less than four weeks in 34% of cases, one to twelve months in 41% of cases and more than a year in 26% of cases. The general practitioners assessed the patient as fully competent in 90% of the cases and partially competent in 7% of the cases. In 50% of cases, the GP was not informed of the decision in advance. 94% agreed with the patient's decision. In 18% of cases they indicated that they themselves had given the patient the idea to stop eating and drinking.

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

According to the respondents, almost half of the deceased in Chabot's study had made a euthanasia request that was not granted. According to the confidential counselors, the doctor's main reasons for this were: the patient was not terminal or there was none

fatal illness (21%), the patient had no illness (4%), the patient did not suffer unbearably or without hope (26%), fear of legal consequences (17%) and the doctor's philosophical view (20%). The Death Surveys for 2010 (Van der Heide 2012-1) and 2015 (Hagens 2021) also show that almost half (43% and 45% respectively) of those who consciously stopped eating and drinking had made a euthanasia request that was not granted. In Bolt's study (2015-1), 19% had requested euthanasia. This request was refused by 14%; in 4%, euthanasia was not performed for other reasons, including objections from the partner. Qualitative research shows that patients who have not made an explicit request for euthanasia often prefer euthanasia to BSTED (Bolt 2023, unpublished).

The role of the GP and relatives in supporting a patient who stops eating and drinking is shown in table 3.3 (Bolt 2015-1).

This shows that more than 30% of general practitioners had no supervisory role at BSTED. In approximately 30% of the cases, no loved one was involved BSTED.

Bolt (2023) conducted a qualitative study through interviews with patients, relatives and caregivers involved in 29 cases of BSTED (Bolt 2023). Nine 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, food and drink were actually avoided; 19 of these patients died.

The patients in this study could be divided into three groups. The first group involved patients who were elderly, but still in relatively good health. They often did not have a death wish, but wanted to prevent losing control due to health decline by stopping eating and drinking. This group hardly involved others in decision-making, which sometimes meant that loved ones were taken by surprise. The second group was elderly people in poor health whose world had become small and who already

had a death wish for a long time. They were largely dependent on their loved ones and caregivers in decision-making and preparation for stopping eating and drinking. The third group consisted of patients with chronic psychiatric disorders, who were often younger than the patients from the other two groups. Their death wish had been present for a long time and had sometimes led to suicide attempts, but it could vary greatly over time. They experienced a lot of resistance from loved ones or healthcare providers regarding their wish to start BSTED, which meant that they often did not involve others in the decision-making and preparation. Because they received no support, they often decided not to start BSTED or to do so in secret.

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

Hoekstra et al. conducted a survey among 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 seeing more than five such patients during this period.

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

Furthermore, there are several publications describing a total of 39 cases of patients who consciously refrained from eating and drinking and subsequently 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. In two cases it was a second attempt (Ann 2016, Koopmans 2012) and in one case a third attempt (Jacobs 2003).

One case (Fewing 2014) with comments from Kirk (2014) and Meisel (2014) describes the dilemmas of an incapacitated patient with dementia, where the daughter insists on no longer offering food and drink. The outcome is not described. De Kort (2017) described two patients with reduced decisional capacity, who stopped offering food and drinks.

Furthermore, two cases are described of patients who started to stop eating and drinking, but later changed their mind and started eating again. The first case was an 81-year-old woman with a subdural hematoma after a fall, COPD and depression that 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 quickly and he continued to be given food in the hospital where he had been admitted (Malpas 2014). Marks (2016) described the process of a patient preparing to discontinue food and fluid.

Table 3.1. Investigating patient data BSTED

	Ganzini 2003	Chabot 2007	Van der Heide 2012-1 (Deaths study 2010)	Bolt 2015-1	Hoekstra 2015	Hagen's 2021 (Deaths survey 2015)	Case studies 1994-2022
Respondents	Hospice nurses	Confidential persons	Doctors	General practitioners	General practitioners and palliative care physicians	Doctors	Doctors, ethicists, relatives
Land	United States (Oregon)	The Netherlands	The Netherlands	The Netherlands	Germany	The Netherlands	Various countries
Frequency estimate BSTED per year		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 (gem.)	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%	
Main diagnosis	60% cancer, 16% cardiovascular diseases and 23% diseases of the nervous system	40% fatal illness, 32% serious somatic or psychiatric illness, 28% defects but no disease	15% cancer, 14% cardiovascular diseases, 16% diseases of the nervous system and 54% other/unknown	27% cancer, 39% other serious physical illness, 12% early dementia, 7% psychiatric illness, 24% no serious physical or psychiatric illness*	58% cancer, 20% neurological disease	61% somatic disorder, 34% dementia, 63% accumulation of old age complaints, 0% psychiatric disorders	23% cancer, 44% neurological disorder, 10% other serious physical illness, 5% psychiatric illness, 18% no serious illness

* multiple answers possible

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

	Chabot 2007 n=97	Bolt 2015-1 in 2 n=99
Somatic		
Weakness or fatigue	53%	60%
Pain	38%	18%
Shortness of breath/fear of suffocation	10%	9%
Physical decline		51%
Other physical complaints		8%
Psychologically		
Depressed/gloomy	10%	16%
Angst		3%
Social		
Loneliness	11%	15%
Loss of a loved one		8%
Dependency		
Dependency	38%	32%
Not wanting to be a burden to 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 communication		11%
Demoralization		
Having no purpose in life	43%	38%
Suffering without any prospect of improvement		41%
Control of dying		
Completed life	59%	40%
Loss of control	25%	27%

* multiple answers possible

Table 3.3. Role of general practitioners and involvement of loved ones in stopping eating and drinking (Bolt 2015-1)

Supervisory role of GP:*	Bolt 2015-1
- In preparation	21%
- In progress (no palliative sedation)	27%
- Palliative sedation until death	28%
- No	38%
Supporting role of relatives:*	
- In preparation	44%
- In progress	53%
- Nee	28%
- Do not know	3%

* multiple answers possible

3.5 Amount

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

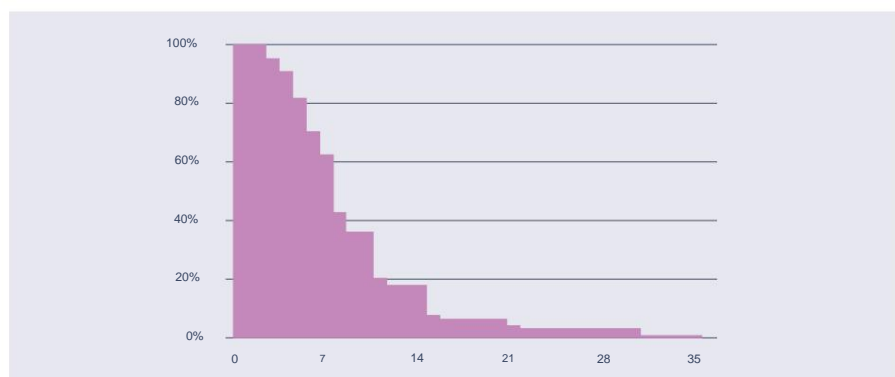
The time until death of the patients in Chabot's study (2007) is shown in table 3.4. In the patients who died within 7 days (n=40), it was uncertain whether they died as a result of stopping eating and drinking or as a result of an illness. They are therefore excluded (for scientific reasons) from the frequency estimate. The cohort described in table 3.1 (n=97) therefore only consists of patients who lived longer than 6 days after stopping eating and drinking. Regardless of the nature of the disease, the median time to death is 13 days. This means that 50% die within 13 days.

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

Duration from not drinking until death	In case of a fatal or serious illness	If there is no fatal or serious illness	Total
<7 day 7-9	40	0	40
day 10-12 day	19	5	24
13-15 day 16-18	17	4	21
day	12	10	22
	3	1	4
19-30 days*	12	3	15
31-60 days* >60 days*	6	2	8
	1	2	3
Total	110	27	137

* These patients continued to drink more than 50 ml daily. Then it is not true-
Apparently the patient will die within 18 days.

The median time to death in the Bolt study (2015-1) 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 BSTED and death (Bolt 2015-1)

In the interview study (n=17 patients) by Eppel-Meichliner (2021), the median time to death was 14 days. In 5 cases, death lasted longer than 3 weeks (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).

In the collected case reports, the median time to death was 11.5 days (range 6-24).

The process leading to death has been divided into 3 phases by Chabot (2007). In the first phase (3 to 4 days), drinking was stopped acutely or gradually. The middle phase was variable in length. Diffuse pain or symptoms of delirium sometimes occurred during this period. Painkillers and sleeping pills were the most commonly prescribed soothing agents during this period. During this phase, some people started drinking again. Thirst was not a prominent complaint and in most cases could be prevented or alleviated by good oral care. The final phase lasted several days and was comparable to the dying phase of a fatal disease.

10% of the confidential counselors spontaneously indicated that the death process had been painful or undignified; 40% spontaneously indicated that it had gone well, peacefully, without pain or with dignity. The other relatives did not provide spontaneous information about the course.

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

The collected case histories also suggest a dying process that is generally acceptable and bearable for the patient and loved ones.

However, the possibility of a selection bias (only publication of cases that went relatively well) cannot be ruled out.

In Bolt's retrospective series (2015-1), 5 of 24 patients reversed their decision to stop eating and drinking. This involved 3 patients under the age of 50 for whom psychological suffering was the reason for BSTED, 1 older patient with psychological suffering and 1 patient with dementia.

In addition, 1 patient committed suicide during BSTED by ingesting lethal substances. In all these cases, the failure or lack of medical supervision played a role. Two cases have been described in the literature in which people started eating and drinking again (Kohlhase 2016, Malpas 2014).

In the retrospective study by Ganzini (2003), 16 out of 126 patients (13%) reconsidered their decision to stop eating and drinking. Other studies provide no information about this.

3.6 Experiences of relatives and informal caregivers

In the previously discussed interview study by Bolt (2022), the following points emerged regarding the experiences of relatives of patients who had consciously stopped eating and drinking:

- Relatives sometimes had great difficulty understanding the patient's decision, especially when the patient had not involved them much during the preparation. Yet the relatives wanted to help the patient, because they saw that this was what the patient wanted.
- Some relatives described a conflict during the BSTED process: they wanted to help the patient 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 complaints, and they had difficulty caring for their loved one to see it deteriorate so quickly.
 - In some cases, relatives felt very responsible for the smooth running of BSTED. Especially as the patient deteriorated, they could sit like a lion next to the bed to ensure that

would not (accidentally) give anyone anything to drink or the patient would suffer unnecessarily.

- The relatives often did not understand when the doctor gave palliative care sedation would start, or why euthanasia was not performed. This could lead to unpleasant situations during the process, in which relatives put pressure on the doctor to sedate the patient or to proceed with euthanasia.
- The relatives needed care and support from healthcare providers, but did not always receive this when BSTED occurred at home.
- If relatives could not properly understand the decision, they could be left with questions and doubts afterwards. They could even be left wondering whether they had done the right thing by cooperating.

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

- A dominant feeling among caregivers was that they should act as the patient's advocate. That means they have the had to defend the choice to stop eating and drinking in relation to the environment. They could only take on this role out of respect for the patient's autonomy and from a conviction that this was the best choice for the patient and that there was no good alternative. However, this sometimes resulted in moral personal dilemmas.
- Partly in connection with the above, informal caregivers were often unsure about the support they received from the environment and from healthcare professionals. They were often dissatisfied with professional care and sometimes felt abandoned.
- Caregivers often experienced increasing responsibility for the process as the patient became weaker and lost focus.

- The informal caregivers often did not know what to expect made different choices regarding their role: either as care provider or as partner or child.

3.7 Opinions of healthcare professionals

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

In a survey of 307 nurses and 83 social workers, all working in a hospice in Oregon (United States), 85% thought 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% thought stopping eating and drinking was immoral and 69% thought stopping eating and drinking was fundamentally different from PAS (physician-assisted suicide).

In the previously discussed German study by Hoekstra (2015), four patient vignettes were presented to the 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 the guidance of the old, tired patient as assisted suicide. Nevertheless, in all four cases the majority of doctors interviewed believed that the patient had the right to medical guidance. In all four cases they showed a great willingness to support the patient.

In Bolt's questionnaire survey, 81% of general practitioners indicated that they found it conceivable to apply palliative sedation to 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) at:

- 1562 nurses in nursing homes (Stängle 2020-1). The response rate was 34%;
- 1616 nurses in home care (Stängle 2021-3). The response percentage 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). The response percentages were respectively 32%, 24% and 45% (overall 40%).

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.

	Stem 2020-1	Stem 2021-3	Stem 2020-2	Stem 2021-1
Target audience	Nurses in nursing homes	Nurses in home care	General practitioners	Nurses in nursing homes and home care general practitioners
Number of respondents	535	395	751	1681
Experience with stopping eating and drinking	48%	40%	43%	43%
Death due to stopping eating and drinking is:				
• a natural death	65%	70%	59%	64%
• passive euthanasia ⁸	26%	17%	32%	27%
• suicide	4%	5%	5%	5%
Respects the decision	97%	97%	97%	97%
Believes that the patient has the right to care	98%	98%	98%	98%
Considers it a dignified form of death	71%	72%	75%	73%
Has moral doubts	13%	14%	22%	17%
Would recommend it to a patient	33%	48%	58%	48%
Personally I would consider it an option	73%	76%	76%	75%

⁸ The term 'passive euthanasia' was used in the article, but is in the Netherlands no longer common nowadays.

Stängle et al. also conducted an interview study using 5 focus groups with a total of 47 healthcare providers (2 general practitioners, 14 nurses in nursing homes, 13 nurses in home care, 18 ethicists, politicians, volunteers and relatives) (Stängle 2021-2). The data from the focus groups were integrated with that from the national survey (Stängle 2021-1).

In addition to the previously discussed themes (see table 3.5), the following was discussed:

- lack of knowledge among some healthcare providers;
- insufficient implementation of care for people who quit eating and drinking in Swiss institutions;
- lack of financial support for (time-consuming) care;
- discussion about stopping eating and drinking in incapacitated patients;
- the importance of consensus within the treatment team and of interdisciplinary plinary coordination and communication;
- giving patients space to reconsider their decision to stop eating and drinking;
- the role of the informal caregivers as the patient's advocate to defend her choice (as also described by the informal caregivers themselves);
- the great burden on informal caregivers and the importance of good care communication with and support from them.

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

4. LEGAL AND ETHICAL ASPECTS

4.1 Summary

- BSTED is a right of everyone who is competent.
- The committee does not rule on whether BSTED is a (specific) form of suicide. The committee notes that BSTED focuses on a number of

distinguishes morally and procedurally relevant points from (other forms of) suicide.

- Care for patients who choose BSTED is palliative care should be offered to everyone. It is not assisting suicide.
- The death of a patient who dies from BSTED is considered a natural death.
- BSTED is an option that can be discussed in discussions about the end of life and/or a death wish.
- The possibility of BSTED can be included in an advance directive as a (possible) wish for the future, but also if the patient has already made the decision to BSTED.
- The representative plays an important role at BSTED if the patient is incapacitated at the time of decision-making or if the patient has become incapacitated after stopping eating and drinking (for example as a result of delirium). The representative is expected to act in the interests and spirit of the patient.
- If a competent patient refuses food and fluid, the healthcare providers involved will refrain from artificially administering and offering food and fluid. • Healthcare providers may refrain from providing care to patients who opt for BSTED based on conscientious objections. In that case, the care provider must transfer the care to a colleague.

4.2 Introduction

This chapter describes the legal and ethical aspects of BSTED.

First, the basis of the competent patient's right to choose BSTED is discussed. It then discusses BSTED in relation to suicide and support for BSTED as a form of palliative care.

BSTED is then placed in the total of proactive care planning and the provision of information to patients is described. This is followed by an explanation of the position of the patient's representative and the role of an advance directive. Then it becomes

discussed differences between administering and offering food and fluid, and conscientious objections among care providers.

4.3 Right to BSTED

People increasingly need control over their own end of life. To this end, people have a number of options, of which BSTED is one.

BSTED is a right of everyone who is competent (Leenen 2020). It is a choice that people can and may make themselves and for which they are not dependent on others. It is not required that a healthcare provider or a loved one is involved in BSTED, although this is strongly advised to guide the process as best as possible.

The basis for the right to choose BSTED is the patient's right to self-determination⁹: the right of the competent patient to make her own decisions about her life and body. This right is included in, among other things, Article 10 of the Dutch Constitution (the right to respect for private life), Article 11 of the Dutch Constitution (the right to physical integrity) and Article 8 of the European Convention on the Rights of Persons. Humanity (ECHR) (the right to respect for private life). In the *Pretty* case, the European Court of Human Rights (ECHR) stated for the first time that the right to self-determination is part of the right to respect for private life (Article 8 ECHR).¹⁰ Just as a refusal to treat must be respected, Likewise, the decision of a competent person to stop eating and drinking must be respected.

⁹ The right to self-determination includes both a right of defense and the right to freedom of choice and the right to self-development.

¹⁰ ECHR 29 April 2002, EJHL 2002, p. 263-279 (*Pretty/United Kingdom*).

Administering fluid and nutrition to competent persons against their will (and thus preventing them from BSTED) would essentially mean that people are forcibly administered nutrition and/or fluid. Various fundamental and human rights oppose this, such as the right to bodily integrity, which is included in Article 11 of the Constitution.

4.4 BSTED in relation to suicide

The question sometimes arises whether BSTED is a form of suicide.¹¹

There are different views on this in the literature. Some authors consider BSTED as (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 BSTED and suicide (Pope 2011, Schmidhuber 2019) and still other authors indicate that it depends on the circumstances (Jansen 2015, Moskop 2021, Schneider 2021). In surveys among Swiss general practitioners and nurses, 95-96% BSTED found no form of suicide (see table 3.5, Stangle 2020-1, 2020-2, 2021-1 and 2021-3).

The above-mentioned articles indicate a number of aspects of BSTED, which would indicate that BSTED is either not suicide or differs from other forms of suicide in a number of relevant points (Den Hartogh 2023):

- 'Let' versus 'do': in BSTED an action (eating and drinking) is omitted, while in suicide an active action (e.g. taking medication, inhaling helium, hanging oneself) is usually performed (Moskop 2021, Pope 2011, Schmidhuber 2019).

BSTED is seen as 'letting oneself die' (Schmidhuber 2019), while suicide can be seen as 'making oneself die'.

- BSTED can be interpreted as refusing treatment (Moskop 2021, Pope 2011, Schmidhuber 2021, Schneider 2021).

¹¹ Parliamentary questions (Appendix) 2015-2016, no. 466

- In BSTED, an internal, natural cause leads to death and a 'normal' dying process occurs (Jox 2017, Pope 2011). So there is no external, unnatural factor.
 - BSTED is not mutilating or violent (Jox 2019).
 - BSTED is gradual. This means that there is time for reflection and that the patient can come back to the decision during the process (Jox 2017, Schneider 2021). By taking in small amounts of fluid, the patient can also partly determine the pace of the process. This gradualness of the process also means that there is room for possible ambivalence regarding the death wish
- to discuss with the patient.
- BSTED requires perseverance on the part of the patient (Jox 2017). This means- knows that there can be no question of an impulsive act (Schneider 2021) and voluntariness is virtually guaranteed. Because the motivation for BSTED comes from the patient himself, there is virtually no chance that BSTED will be performed under pressure from others.

The committee notes that there are differing views in the literature on the question of whether BSTED is a (specific form of) suicide. The committee makes no ruling in this discussion. The committee does note that BSTED differs from (other forms of) suicide on morally and procedurally relevant points. The committee believes that is an answer to this question is also not necessary. Even if BSTED is seen as a special form of suicide, the care that should be provided is not assisted suicide. The committee sees this as palliative care, which should also be provided in other situations where people are suffering. This is explained in the next paragraph.

4.5 Support for BSTED as a form of palliative care

Competent patients have the right to choose BSTED. In that respect, the guidance of people who stop eating and drinking can be equated to the guidance of people who refuse treatment.

Healthcare providers who provide patient care at BSTED respect the patient's autonomous decision and keep the patient comfortable. The care and support for a patient who has chosen BSTED is aimed at adequately and proportionately relieving the patient's suffering, not at causing or accelerating the end of life. The guidance of people at BSTED is therefore not assisted suicide.

Palliative care for people who have opted for BSTED may, under certain circumstances - as described in the Palliative Sedation Guideline - also mean that palliative sedation is an option. In the opinion of the committee, the argument that palliative sedation is not permitted because people could relieve their suffering by starting to eat and drink again (and therefore there is no refractory symptom) is not tenable. It is time to start eating and drinking again

after all, this is not a reasonable alternative for the patient. Not dying can be seen as an unacceptable 'side effect' of starting to eat and drink again. As a result, there may indeed be a refractory symptom and therefore an indication for the use of palliative sedation. If the patient consumes little or no fluid, the criterion of an estimated time until death of a maximum of two weeks ([Palliative Sedation Guideline](#)) is also met.

In the committee's opinion, there is no morally relevant distinction between palliative care for people who opt for BSTED and palliative care in other situations, for example when refusing (other) treatment, such as antibiotics for pneumonia or discontinuation of dialysis. After all, such a distinction would mean that people who choose BSTED are denied adequate symptom relief.

In the committee's opinion, 'own fault' should not play a role in considering whether someone's complaints should be remedied. All people who suffer have the right to relief from that suffering, even if that suffering is the result of their own choice, such as BSTED.

A patient who chooses BSTED does not consent to the provision of life-prolonging care (including offering food and drinks and the artificial administration of nutrition or fluid). However, she can give permission for the relief of complaints.

Failure to provide palliative care at BSTED could be legally qualified as contrary to Article 255 of the Criminal Code: abandoning a person in need of care. This article reads: "Anyone who intentionally places or leaves in a helpless state a person to whose maintenance, nursing or care he is obliged by law or agreement, shall be punished with a prison term of not more than two years or a fine of the fourth category."

The death of a patient who dies by consciously stopping eating and drinking is considered a natural death and therefore does not have to be reported to the municipal coroner. The direct cause of death is stated in the death certificate as 'consciously stopping eating and drinking'. A death due to BSTED does not have to be reported as a disaster.

4.6 Proactive care planning

It is important that healthcare provider and patient discuss the end of life in a timely manner (see the [Proactive Care Planning Guideline](#)) (KNMG 2021-3, Rietjens 2017). In these conversations, the values, wishes and needs of the patient as well as the responsibility, (im)possibilities and limits of the care provider with regard to the end of life can be discussed. It is important to also involve the patient's representative (see section 4.9) in this conversation, if this is desired by the patient.

This conversation is not always easy for both patients and healthcare providers. However, it is important to have this conversation in a timely manner, because it allows mutual expectations and misunderstandings to be discussed

can be prevented about what is appropriate and feasible care in the final phase of life and what the care provider is and is not prepared to do.

The doctor can use, among other things, the [KNMG guideline *Talk about the end of life in a timely manner*](#) (KNMG 2021-1). This guide contains talking points that allow the doctor to explore the patient's questions and expectations. This guide has been developed for doctors, but can also be used by other healthcare providers. There is also a [public version](#) of this guideline was developed (KNMG 2021-2).

It often happens that people want to explore options for maintaining control over their own end of life and want to discuss this with a care 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 wish to die, it is important to carefully inquire into the background of this wish. Sometimes a death wish conceals a request for help. The death wish can also arise from a mental illness or existential need. In that case, it may be advisable to refer to mental health care, a spiritual counselor or another form of assistance (see also section 5.5.2).

4.7 Information provision about BSTED by healthcare providers

If a competent patient wants to explore options surrounding the end of life or has a well-considered death wish, the care provider will initiate a conversation in which the request for assistance is explored (KNMG 2021-1).

In these conversations, the healthcare provider discusses the patient's options, including the possibility of BSTED. In that situation, healthcare providers may also raise the possibility of BSTED themselves, of course to the extent relevant to the patient in question. After all, it is the healthcare provider's responsibility to enable patients to make a well-considered decision about their own end of life. This also results from the

Medical Treatment Agreement Act (WGBO). In this way they respect the patient's autonomy. After all, autonomy not only means that healthcare providers respect the wishes of patients as much as possible, but also that they provide patients with information that enables them to make a decision that fits their own life history.

For a well-considered decision, it is important that patients are well informed about the various options available at the end of life and about their advantages and disadvantages. Must be prevented patients make decisions based on incorrect information and considerations.

There is sometimes unfamiliarity and misunderstandings in society about (the process of) BSTED. For example, people may think that BSTED always involves a lot of suffering. However, research and experience show that with good preparation and guidance during the process, this is usually not the case (see Chapter 3, Empirical data).

Healthcare providers therefore have the responsibility to inform competent patients with questions about end-of-life options or a well-considered death wish and their loved ones about all options relevant to the patient, including (if applicable) BSTED. If BSTED is discussed, the healthcare provider will provide information about the preparation and progress of the BSTED process, the 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 care provider also provides information about the professional help and support that can be offered.

Providing information can also consist of pointing out books, public brochures and reliable websites where information about BSTED can be found (see section 5.2). Consultation and possibly the active involvement of experts, for example in the field of palliative care or spiritual care, may be appropriate in this information process.

Informing patients about BSTED is not an incitement to suicide. After all, these are competent patients who need information about end-of-life options and want to discuss them. By educating the patient, the patient is given tools to make an informed, well-considered decision about his or her own end of life.

4.8 The role of an advance directive at BSTED

As part of proactive care planning, the patient can draw up an advance directive. The patient can, for example, indicate that she wants to refrain from (specific aspects of the) treatment. This concerns a so-called treatment ban. A written advance directive can also include (the possibility of) BSTED.

Two situations can be distinguished with regard to an advance directive at BSTED:

1. The patient indicates that stopping eating and drinking is his wish for the future. This may, for example, concern people with a gradual cognitive disorder (such as dementia), who are still competent at the time the advance directive is drawn up.
The role of a previous advance directive regarding not offering or administering food and fluid to people who have become incapacitated during the course of the disease process is discussed in Chapter 7.
2. The patient has already decided on BSTED and records that decision in writing. Such an advance directive can, for example, indicate how healthcare providers and relatives should act if the patient asks for fluids in a delirious (and incapacitated) state. People who start BSTED are recommended to draw up such a declaration of intent, in case they become incapacitated during the BSTED process, and to discuss this with the representative. However, it is not a requirement (see section 5.6.4).

4.9 The position of the representative of the incapacitated patient

If the patient becomes incapacitated during the BSTED process, she will have to be represented by another person (see section 5.6.4). The authority to decide on the treatment and care of the patient then passes to that representative.

The WGBO prescribes that (in hierarchical order) the following are eligible as representatives: the patient's legal representative (curator or mentor); if this is lacking, a personal representative; if this is missing, the spouse, partner or life companion; and if this is missing, the parent, child, brother or sister, grandchild or grandparent (Article 7:465 of the Dutch Civil Code).

The patient's representative (in practice usually the partner or a child) is expected to make decisions about the care and treatment of the patient when he or she is no longer able to do so. The representative is expected to act as a 'good representative' and to act in line with any written advance directive, previous oral statements or a previous decision by the patient. A 'good care provider' is expected to ensure that the representative represents the patient's interests and that the care provider will discuss this with the representative if doubts arise about this. A previously drawn up advance directive about the desired care in a situation of delirium or in another situation can be helpful for both the representative and the care provider.

In principle, the responsible healthcare provider must follow the representative's decision, unless this would conflict with the 'care of a good healthcare provider'. On this basis, it has the authority to deviate from the representative's decision. For example, this is on

the order when the responsible healthcare provider judges that the representative is not acting in the interests or mind of the patient. The responsible healthcare provider must coordinate such a decision with other healthcare providers involved (multidisciplinary) and record it in the medical file with reasons. It is advisable to consult one or more (not involved) colleagues in advance when making such a decision. The representative will be informed about this.

4.10 Offering versus administering food and fluid

If a competent patient chooses BSTED, relatives and care providers refrain from offering food and drinks and administering nutrition and fluid during this process (see also section 2.4). The care provider must respect the wishes of the competent patient and not offer or administer food and fluid if the patient has indicated that he or she does not want this.

In general, not artificially administering fluids and nutrition will raise little discussion in this situation. The artificial administration of fluids and nutrition is regarded as a medical treatment, for which the (competent) patient has the right to refuse under the WGBO.¹²

Not offering food and drinks to patients who opt for BSTED can cause emotional problems for relatives and caregivers, because they may see food and drinks as a form of basic care that they cannot and do not want to deprive the patient of. If necessary, healthcare providers can then appeal to conscientious objection, provided that the patient does not suffer any serious harm from this (see next section).

¹² Article 7:450 member 1 BW.

4.11 Conscientious objection

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

Although the guidance of people who choose BSTED is a form of palliative care, some healthcare providers may experience that they provide poor care and/or facilitate the patient to hasten the end of his life. This may pose conscientious objections for a healthcare provider.

In that case, the patient's choice conflicts with the care provider's beliefs or personal values and standards.

Caring for a patient generally means making sure someone is eating and drinking enough. This also applies to healthcare providers. Eating and drinking is more than nutrition. Eating and drinking refers to life and also to living together. Stopping offering food and drinks because the patient chooses to hasten the end of life can give caregivers the feeling that they are providing poor care.

However, the care provider has the duty to act as a 'good care provider', even if she does not agree with a choice made by her patient that leads to health problems and/or hastens the end of life. A patient should not be deprived of appropriate care that comes with consciously stopping eating and drinking. If a healthcare provider has conscientious objections to providing this care, she must transfer the care of the patient to a fellow healthcare provider. The patient is informed about this. A healthcare provider who invokes conscientious objections must provide care until the moment of transfer to this colleague.

The [KNMG Code of Conduct for doctors](#) is also in this light (2022) is important: 'If, as a doctor, you cannot respond to the patient's request for help because of your conscience, you inform her or him of this and put her or him in touch with a colleague. An appeal to your conscience should not lead to serious harm to the patient.' (Core rule 11, KNMG 2022).

The [Professional Code of Nurses and Caregivers](#) says the following about conscientious objections (Article 2.5):

As a nurse/carer, I have the right to refuse to cooperate in certain treatments based on conscientious objections. This means, among other things, that I:

- refuse to cooperate with actions that bring me into serious conflict with my philosophy of life or personal sense of values and standards;
- express my conscientious objections in a timely manner, where possible;
- in the event of conscientious objections, provide motivated care to my manager or, if there is no manager, to one of my colleagues;
- as a self-employed person, report my conscientious objections to the care recipient (or other involved parties) and provide care until it is taken over;
- provide care that is not directly related to the act or intervention to which I have conscientious objections, unless that care is also taken over by a colleague.

PART 2

Care for people who consciously 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 loved ones and involve them in decision-making, preparation and implementation.
- Check in all phases whether there is any overload on loved ones and whether support is necessary for this.
- Also pay attention to the emotions and burden of the person involved healthcare providers.
- If necessary, consult the [palliative care guidelines](#) and other relevant ones guidelines.
- If necessary, ask for advice, for example from a palliative consultation team care or to a spiritual counselor.

Decision

- Check which factors underlie the decision to BSTED; consider interventions (if possible and desired by the patient) and, if necessary, consultation, for example with a palliative team, geriatric specialist, spiritual counselor, psychologist or psychiatrist.
- Inform the patient as well and objectively as possible about the expected course and the pros and cons of BSTED; also inform the patient of expected problems; indicate where good and reliable information can be found.

- Advise against stopping eating and drinking without proper preparation and support from loved ones (if available) and/or healthcare providers.

Preparation

- Inform patient and relatives;
 - about how to stop eating and drinking;
 - that hunger usually disappears within a few days and thirst can often be alleviated by good oral care; - that there is always room and opportunity during the process to revisit 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 can take longer if some drinking continues or in young patients (< 60 years) if there is no life-threatening illness ;
 - that good oral care, sleeping medication and sometimes pain relief and tranquilizers are essential;
 - that there is often very variable, but gradually increasing drowsiness and that this may also involve confusion (delirium);
 - that palliative sedation can be used in some situations, but only in the course of the process, if at that moment there is unbearable suffering due to one or more refractory symptoms
- If necessary, ensure that the bed is adjusted (preferably a high-low bed), an anti-decubitus mattress, oral care products, a bedpan, urinal or incontinence material and, if necessary, products for an enema; If necessary, consult with a cardiologist about switching off an ICD.
- Pay attention to:
 - tangible and intangible matters that are still arranged or finalized works need to be done;
 - say goodbye;
 - the wish for rituals before and/or after death, the course of events after death (physical care, clothes, laying out) and the

arranging and organizing the funeral/cremation.

- Adjust medication:
 - Continue only the strictly necessary medication.
 - Anticipate problems that may arise and prescribe the necessary medication.
 - Prescribe medication that can be given transmucosally (sublingual, buccal, oro-mucosal or intranasal), transdermal, sc, IV or possibly rectally.
- Check whether care can take place at home; if not, consider transfer to a hospice or palliative unit (provided they are willing to provide the care).
- Provide the necessary and desired care (nurses, caregivers, family help, domestic support, volunteers and/or spiritual care); check whether all healthcare providers involved are prepared to provide care to patients who consciously stop eating and drinking; inform the patient and relatives about who is present and when and about their accessibility; ensure proper coordination of care and documentation in a file available with the patient.
- Recommend drawing up an advance directive, in which the patient documents:
 - that she consciously stops eating and drinking to end her life soon;
 - that she does not want to be admitted to a hospital;
 - that she does not give permission for the offering of food and drinks and the artificial administration of food and fluid;
 - that she refrains from life-prolonging treatments (including resuscitation) mate);
 - how to act if she asks for fluids in a delirious state.
- Ensure that a representative is appointed.

Executive phase: initial phase

- In consultation with the patient, reduce eating (usually immediately) and drinking (immediately or gradually, over a few days).

- Start body, skin and oral care. If possible and desired, involve your loved ones in this.
- Talk to the patient if she indicates that she cannot continue or wants to change her decision to give up eating and drinking.

Executive phase: middle phase

- Pay a lot of attention to oral care.
- If the patient can no longer use the baby chair or toilet, provide a bedpan, urinal, incontinence material, mat, condom catheter or indwelling catheter.
- Check whether the rectum is full and, if necessary, give bisacodyl supp. Or a (mini) enema.
- If necessary, treat complaints such as pain, dyspnea, nausea, vomiting, restlessness, confusion and delirium.
- Only use continuous palliative sedation if there is unbearable suffering during the course of the treatment due to one or more refractory symptoms and if the patient has demonstrated that he/she can actually stop drinking; otherwise the condition of life expectancy < 2 weeks is not met. If in doubt, short-term ('time-out') or intermittent sedation can be chosen.

Executive phase: dying phase

- Mark the stage of death and inform the patient (if still alive). spoken), the relatives and the healthcare providers involved about this.
- Treat complaints and problems (e.g. terminal delirium, rattling) accordingly the palliative care guidelines.
- After death, issue a declaration of natural death, true 'stop eating and drinking' is entered as the direct cause of death.

- Offer an appointment for a follow-up discussion with loved ones.

Evaluate the entire process with the healthcare providers involved and offer advice space for emotions.

5.2 Introduction

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

- doctors, in practice mainly general practitioners, geriatric specialists skills and hospice physicians;
- physician assistants;
- nurse specialists;
- nurses and/or caregivers;
- spiritual counselors;
- volunteers.

In addition to the above-mentioned people, family members and/or other confidants (collectively referred to as relatives) play a crucial role in care and guidance. Below we first discuss the role of relatives. The remainder of the chapter discusses the professional aspects of decision-making, guidance and care. The organization and coordination of care are essential.

Professional caregivers, volunteers and loved ones share responsibilities. Professionals can be expected to take the lead in this feed.

By guiding and caring for the patient, caregivers and loved ones 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, in which mutual coordination between healthcare providers, and between healthcare providers on the one hand and patients and relatives on the other, is central. It is wise that the responsible healthcare provider, if necessary, calls on, collaborates with and/or requests advice from experts, such as geriatric specialists, physician assistants, nurse specialists,

nurses, caregivers, spiritual counselors and/or palliative care consultation teams. When a healthcare provider has doubts about her own expertise, it is always the professional standard to consult the right expert in a timely manner. This expertise is accessible and available to all healthcare providers.

Lack of cooperation and coordination can have major consequences for both the patient and their loved ones and the healthcare providers. It is therefore very important that good agreements are made between all those involved.¹³ Care providers record relevant data relating to the patient in the file. The treating physician ensures an adequate transfer to the replacement physician and other healthcare providers involved, especially during evening, night and weekend hours.

The healthcare providers involved should be easily accessible and available to the patient. Physician assistants, nursing specialists, nurses and caregivers also ensure a good transfer.

A number of recent reviews pay attention to the decision-making, preparation and implementation of BSTED (Ivanovic 2014, Lowers 2021-1, Gruenewald 2018 and 2020, Quill 2018-1 and 2018-2, Wax 2018). As far as we know, there are no other national or international guidelines or guidelines in this area (Mayers 2019). Gruenewald (2018 and 2020) provides extensive practical information about BSTED in nursing homes.

This guide is primarily written for doctors, physician assistants, nurse specialists, nurses and caregivers, but can also be read by other professional healthcare providers, volunteers, patients and loved ones. The use of words and terminology are

¹³ See also [Guidelines for the division of responsibilities in collaboration in healthcare, revision 2022](#).

however, tailored to doctors, physician assistants, nursing specialists and nurses. Patients and loved ones can find information in the book 'Uitweg' to guide and care for the patient as best as possible during the process of consciously stopping eating and drinking (Chabot 2022). Furthermore, the [brochure 'Consciously quit](#)

[food and drink'](#) of the NVVE (2022) will be used, as well as the [podcast with a conversation with Eva Bolt](#).

5.3 The role of loved ones

Research shows that people who want to opt for BSTED often discuss this wish with one or more confidants or loved ones before approaching a doctor (Bolt 2023, Chabot 2007 and 2009, Eppel-Meichlinger 2021, Lowers 2021-2). These loved ones¹⁴ are emotionally connected 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

die.

The conversations between people with a death wish and their loved ones do not always result in a request for dying assistance from the care provider. If this does happen, it may take the form of a euthanasia request or a request for palliative support in stopping eating and drinking. The role of relatives as an intermediary between patient and care provider is essential. They can provide insight into remaining possibilities or limitations. Moreover, people considering BSTED may reconsider taking this path if their intimates are not willing or able to provide care and support. Opposition by relatives to the patient's wish to die can play an important role in the death of the patient

¹⁴ Often one of the relatives is more intensively involved in the decision-making process as a 'pivot' the others. Yet 'neighbors' are spoken of in the plural here, because the wider circle is a sounding board for this pivot and is also involved in care after a decision has been made.

decision-making, in which the doctor can sometimes play a mediating role.

This resistance could also impact the implementation of the BSTED process.

When people choose BSTED, their loved ones play a crucial role on a day-to-day basis.

They often take turns and are often involved in (oral) care. They are also the eyes and ears of healthcare providers when identifying symptoms and complaints and assessing whether they are sufficiently under control. As a care provider involved, it is important to work well together and coordinate with the healthcare provider

relatives.

5.4 Care and guidance per phase

The care and guidance are described per 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 several days), in which acute or gradual stopping eating and drinking;
 - the middle phase (very variable in length, partly depending on the physical condition at the start and the speed and extent to which eating and drinking is reduced);
 - the dying phase (the last days before death and shortly after passing away).

In practice, these phases cannot be strictly separated and often merge gradually.

Some preparations are not yet completed or even started when the patient stops eating and drinking.

Sometimes the healthcare provider is only involved when the patient has already stopped.

In that case, all aspects discussed in section 5.6 in the preparatory phase will only be discussed during the implementation phase.

5.5 Decision Making

5.5.1 Determining legal capacity in this regard

It is important that the patient is mentally competent and makes a well-considered decision. The decision to stop eating and drinking is a decision that places high demands on the patient's decision-making skills and for which determining the decision-making capacity may be appropriate (see also the [guideline Decision-making skills and decision-making capacity of the patient](#)). [Long-term Care Quality Impulse Foundation, SKILZ](#)). To determine the legal (in)capacity, reference is made to the KNMG step-by-step plan (KNMG 2004). The SKILZ decision-making skills and decision-making guide also provides a step-by-step plan. See also Chapter 2.

The patient does not have to prove that she is mentally competent. It is the care provider who must demonstrate that the patient is no longer considered capable of reasonably assessing her interests in this regard (see section 2.3). If there is any doubt about legal capacity, it is advisable (but not mandatory) to consult a colleague, geriatric specialist or a psychiatrist. For information about stopping offering food and drinks to incapacitated patients, please refer to Chapter 7.

5.5.2 Exploration of factors underlying the decision to BSTED

If a patient indicates that they want to stop eating and drinking, it is investigated which factors underlie the decision to BSTED and whether interventions or consultation (e.g. from a palliative team, psychologist, psychiatrist or spiritual counselor) are possible and desirable.

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

- a. physical or psychological symptoms that are not under control;
- b. depression, eating disorder or other mental health conditions;
- c. existential problems;

- d. a rejected euthanasia request;
- e. pressure from outside.

Re a) If the wish to die arises from physical or psychological symptoms (e.g. pain, dyspnea or anxiety) that are not under control, the care provider explores whether treatment is possible and whether this treatment is desired by the patient.

Re b) The wish to die may also be related to a psychological condition that the patient (possibly) has, for example depression or an eating disorder. In such a case, the health care provider questions to what extent the decision to stop eating and drinking is made under the influence of that (suspected) psychological condition. This often requires further diagnostics by a specialized healthcare provider.

In that case, the care provider can refer to specialized care or emergency care provided by the Mental Health Service. If the patient is already aware of a mental illness and is already being treated for it, the healthcare provider will consult with the practitioner to gain an idea of the influence of that condition to the death wish. In principle, the patient's consent is required for this, but in emergency situations consultations can take place without the patient's consent.

The fact that the patient has a mental illness does not necessarily mean that the patient cannot decide to stop eating and drinking, even if the wish to die is (partly) motivated by the mental illness. The patient may nevertheless be legally competent with regard to her death wish and has the right to choose stop eating and drinking. The [decision-making skills and decision-making guideline](#) van SKILZ mentions the criterion 'freedom from coercive influences from within'.

In practice, the question arises whether the care provider can oblige her to do so if the patient does not want diagnosis and treatment. These questions cannot be answered in advance. This will depend on the

circumstances of the case. Given the fact that BSTED poses an acute risk to life, in exceptional cases in the event of a mental disorder, involuntary care can be considered as a last resort. The Compulsory Mental Health Care Act (Wvzgz) then applies. See also www.dwangindezorg.nl.

Ad c) As discussed in Chapter 3 (Empirical data), existential factors often play a role in the decision to abstain from eating and drinking. During the conversation, the care provider explores whether this is the case and whether consultation with a spiritual counselor is appropriate and desirable.

Ad d) Someone'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, the battle about it can shift to whether or not to eat and drink. This disappointment and sometimes anger can make preparation and guidance a difficult process for the patient and the care provider (Van Aarnhem 2011-1 and 2011-2). Sometimes this leads to a disturbed relationship between healthcare provider and patient. It is therefore important to continue to make attempts to restore the relationship and to (continue to) inform the patient about the reason why the euthanasia request cannot be granted.

It goes without saying that a euthanasia request that is not granted does not prevent a process with BSTED. The committee assumes that the euthanasia request cannot be granted because the due care requirements for euthanasia have not been met ([see KNMG position Decisions regarding the end of life \(2021-3\)](#)). If the situation has changed and the due care requirements may be met, the request for euthanasia can be reconsidered.

Some people prefer BSTED to euthanasia because they do not want to be dependent on a doctor to fulfill their death wish, do not want to burden someone else with carrying out euthanasia or have principled or emotional objections to euthanasia.

Ad e) In the conversation with the patient, the care provider explores whether the decision to refrain from eating and drinking is an autonomous decision of the patient and whether there is no external pressure. If there appears to be pressure from outside, the care provider will discuss her motives with the patient, and possibly also with relatives. The starting point is always the patient's wishes. Assistance can be obtained if necessary.

5.5.3 Role of relatives and healthcare providers in decision-making

The patient will often have already spoken to relatives about the wish to die and the intention to stop eating and drinking. However, sometimes the patient needs to be encouraged to do so. The BSTED process requires good care. Patients should therefore be advised not to stop eating and drinking without proper preparation and support from healthcare providers and loved ones (Chabot 2013, Quill 2012, Schwarz 2007). After all, the patient becomes weakened, becomes in need of assistance and the symptoms that arise as a result of not eating and drinking probably cannot be sufficiently relieved without help. In addition to support, care and nursing by loved ones, volunteers, caregivers and/

or nurses, medical guidance 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 BSTED. The healthcare provider also informs the patient of expected complaints and problems, especially if the patient is young.

The (possible) advantages of BSTED are that:

- the patient largely has control over the decision and implementation has and that she is therefore not dependent on others;
- in the case of a death wish, this is a path to death, if euthanasia is not possible or not desired by the patient;
- consciously stopping eating and drinking will certainly lead to death, if there is consistently not eating or drinking;

- the patient can still come back to her during the BSTED process decision;
- the gradual and sometimes lengthy course of the BSTED process makes it possible to say goodbye properly.

The (possible) disadvantages of BSTED are that:

- it may take 1-3 weeks and sometimes longer before the patient arrives passing away;
- complaints occur during this period, which are sometimes difficult to relieve;
- the relatively long duration until death can be stressful for the patient patient and/or relatives.

In the earlier version of this guide from 2014, BSTED was advised against for people younger than 60 years of age. The reason for this was that there were no case studies of people under the age of 60 who ended their lives due to BSTED. However, several cases have now been described that show that people younger than 60 can also end their lives by stopping eating and drinking (see Chapter 3, Table 3.1). The committee therefore no longer applies an age limit to advise against stopping eating and drinking.

However, for people who are younger than 60 years old and who do not have a life-threatening illness, 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. In addition, the ability to concentrate urine is greater at a younger age, which means that dehydration occurs later. In addition, younger people have a stronger sensation of thirst, which makes it more difficult to stop drinking.

In older people, BSTED 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 can also consist of pointing out the importance of good and reliable information, where it is available (see section 5.2, last paragraph) and sharing experiences that the healthcare provider has had with other patients. During this conversation, the patient can also be made aware of other options for a humane end of life. Discussion of this falls outside the scope of this guide.

5.6 Preparatory phase

The preparatory phase covers:

- information, preparation and support for patients and relatives;
- adjustment of medication;
- organization and coordination of care;
- drawing up an advance directive and appointing a representative.

It goes without saying that not all aspects mentioned above need to be discussed in one conversation. Some are not applicable in specific situations, others cannot (yet) be discussed properly 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, physiotherapist assistant or nursing specialist, preferably together with a nurse and/or caregiver.

During the preparatory meeting it will be discussed that:

- eating can be stopped quickly and the feeling of hunger usually disappears within a few days;
- with regard to drinking, you can choose to reduce your drinking or stop abruptly (see section 5.7.1);
- thirst and dry mouth can usually be relieved by good exercise oral care;
- there is always room and opportunity to come back during the process on the decision to abstain from eating and drinking;
- most people die within 1-2 weeks from the moment

they no longer or hardly drink anymore, but that the duration of this period is influenced by the physical condition at the time that eating and drinking is stopped, and that it can take weeks or even several months before death if people do drink fluids. continue to take;

- the BSTED process is expected to be more difficult and longer in young patients (< 60 years), who do not have a life-threatening illness;
- good oral care, sleeping medication and sometimes pain relief and tranquilizers are essential;
- there is often highly variable, but gradually increasing drowsiness and that this may also involve confusion (delirium);
- discomfort and suffering cannot always be avoided even with maximum support to have come;
- palliative sedation can be used in some situations, but only if there is a refractory symptom during the course of the process.

The preparatory conversation determines to what extent the relatives support the patient's decision. Relatives sometimes cannot accept the patient's decision. There may also be feelings of guilt, feelings of having been shortchanged, misunderstanding or anger about the patient's decision. In such situations it is good to discuss this. Good support and guidance of the patient by their loved ones are essential to ensure that the process runs as smoothly as possible. Ambivalence or resistance from loved ones makes the process much more difficult for everyone involved.

The following is also examined during the conversation: • in

the case of an admitted patient: whether the patient is at home or in the hospice, want to die in a nursing home or hospital and whether the option to do so is available;

- if the patient is at home: whether the 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 care unit may be considered. It must be checked whether this is the case

relevant hospice or palliative unit is prepared to provide care for a patient who consciously stops eating and drinking to hasten the end of life.

As discussed in section 5.5.2, a rejected euthanasia request can complicate the process and it is essential to discuss this with both the patient and their relatives. A reconsideration of the euthanasia request is appropriate if the situation has changed

the due care requirements may now be met.

It is important to discuss how relatives and caregivers can deal with the patient's requests to drink. In such situations, the patient is first asked whether he or she is sure that she wants to drink. If the answer is affirmative and if the patient is competent to make the request, the request will always be granted. After all, the patient must have the opportunity to change her decision. A special situation arises if the patient asks for fluid in a delirious state (see section 5.8.5).

Furthermore, attention is paid to:

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

The conversation may also discuss:

- financial/legal arrangements that still need to be made (for example will, authorization for payments, etc.);
- drawing up an advance directive and appointing

a representative (see 5.6.4);

- other (tangible and intangible) matters that still need to be arranged or completed;
- say goodbye;
- wish for rituals before and/or after death;
- course of events after death (physical care, clothes, laying out);
- arranging and organizing the funeral/cremation.

The following can be used to support the patient and their loved ones:

- in the home situation:
 - nurses and/or home care caregivers (if applicable) wishes and not yet involved); check whether these healthcare providers are willing to care for a patient who consciously stops eating and drinking;
 - domestic support;
 - Palliative Terminal Care volunteers (VPTZ); These volunteers are trained and educated to monitor, babysit, assist with practical care, inform patients and provide emotional support, take on incidental care tasks and identify and report changes in the care situation.
- mental caretaker; This can play an important role in, for example, questions about meaning, unfinished business, guidance and support for loved ones, wishes for rituals surrounding the death and discussing and shaping the cremation or funeral. See also the [Directive Meaning and spirituality in the palliative phase.](#)

5.6.2 Adjustment of medication

- Medication for which there is no (or no longer) indication (for example statins, diuretics, antihypertensives, anticoagulants, antidiabetics or bisphosphonates) is discontinued. Only medication that is aimed at existing complaints, such as pain, shortness of breath or nausea, will be continued. • Medication that may cause withdrawal symptoms when discontinued (opioids and benzodiazepines) are continued, especially when

these have been given for a long time and/or in high doses.

- Corticosteroids (prednisone or dexamethasone) are preferred discontinued in view of their appetite-stimulating effect, unless this medication is necessary to combat neurological complaints or other symptoms. If the patient has used the corticosteroids for a long time (> 4 weeks) or in high doses (dexamethasone: > 4 mg/day, prednisolone: > 30 mg/day), they are reduced and discontinued over a number of days to a week. These agents can be administered subcutaneously during the tapering period.
- Anti-epileptic drugs are in principle discontinued unless estimated that there is a high risk of seizures in the deathbed. In that case, valproic acid rectally or levetiracetam sc can be given as maintenance. In case of seizures, midazolam is given intranasally or possibly subcutaneously.
- The medication is no longer oral, especially during the course of the process administered. Alternative routes of administration are:
 - rectal. A number of drugs can be administered as a suppository. Sometimes oral dosage forms can also be given rectally; This applies, for example, to temazepam. Diazepam can also be given as a rectiole. In some cases, different doses are given rectally than orally. A disadvantage of rectal administration is that it can be difficult for severely debilitated patients to place them in the position required for administration and that the agents sometimes come out before they have been reabsorbed in the rectum. The rectal route of administration is therefore not preferred;
 - via the mucous membranes of the oral and nasal cavities (transmucosal):
 - sublingual (under the tongue);
 - buccal (via the buccal mucosa);
 - oromucosal (via the mucous membrane of the gums);
 - intranasally (via the nasal mucosa).
 - transdermal (as a patch);
 - subcutaneously (under the skin), as intermittent injections or continuously subcutaneous infusion using a pump. This is used

made from a subcutaneous indwelling needle. A condition for intermittent administration is of course that someone is available to give the subcutaneous injection at the agreed time(s);

- intramuscular (in the muscle). However, intramuscular administration of medication is rarely or never necessary. An intramuscular injection can be painful. Almost all agents that are 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 strongly preferred.
- The following medication is also prescribed:
 - medication to help you sleep;
 - painkillers for acute pain;
 - if deemed necessary: other medication for complaints that the patient may experience in the short term (e.g. shortness of breath, delirium, seizures or anxiety).

All these medications are taken as indicated. After proper explanation, the medication can be given under the patient's own management (provided there are no cognitive problems).

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

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

Indication	Resources	Non-oral route of administration	
Pain Maintenance Treatment	Paracetamol	Rectal	
	Slow release morphine of slow release oxycodone	Rectal (resorption uncertain)	
	Immediate release morphine or oxycodone	Intermittent or continuous sc or iv	
	Fentanyl	Transdermal (patch)	
	Buprenorphine	Transdermal (patch)	
	Breakthrough medication	Immediate release morphine	Rectal, sc or iv
		Immediate release oxycodone	S.c. of i.v.
		Fentanyl	Sublinguaal (Abstral®, Received®) Oromucosal (Effentora®) Buccaal (Actiq®) Intranasaal (Instanyl®, sin ®)
		Buprenorphine	Sublingual
Nausea and vomiting	Metoclopramide	Rectal, sc or iv	
	Haloperidol	Buccaal, s.c. of i.v.	
	Levomopromazine	Buccaal, s.c. of i.v.	
Constipation	Bisacodyl	Rectal	
	Sodium lauryl sulfoacetate	Rectal	
	Phosphate enema	Rectal	
	Methylnaltrexon	S.c.	
Delirium	Haloperidol	Buccaal, s.c. of i.v.	
Sleep problems, anxiety and sedation	Temazepam	Rectal	
	Midazolam	Intranasaal, buccaal, s.c. of i.v.	
	Lorazepam	Sublinguaal, s.c. of i.v.	
	Diazepam	Rectal or iv	
	Clonazepam	Sublinguaal, s.c. of i.v.	
	Levomopromazine	Buccaal, s.c. of i.v.	

5.6.3 Organization and coordination of care

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

- the willingness and involvement of healthcare providers and relatives, and their mutual division of tasks and responsibilities;
- how often and at what times healthcare providers, volunteers and relatives are present. The content of these agreements depends on a) the patient's wishes, b) her physical condition (which will increasingly deteriorate in the course of the process) and c) the presence and willingness/ability of relatives to provide care. In most cases, someone (a loved one, volunteer and/or care provider) will be continuously present 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:

- good transfer within all disciplines involved, guaranteeing continuity of care, even outside office hours;
- record who the first contact person is;
- interdisciplinary consultation moments and consultation with the patient and relatives;
- drawing up a care plan;
- good reporting of daily details and agreements made, preferably in a central file (in the home situation the care file of home care) or in a care path.

5.6.4 Written declaration of intent and appointment of representative

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

- that she consciously stops eating and drinking;
- that she does not want to be admitted to a hospital;
- that she does not give permission for the offering of food and drinks and the artificial administration of food and fluid;
- that she refrains from life-prolonging treatments (including resuscitation mate);

- how to act if she asks for food and drink in a delirious state;
- who is the representative if the patient becomes incompetent.

An advance directive may be drawn up and written down by someone else, but must be signed by the patient himself.

If necessary, the text can be recorded by the patient in an audio-visual recording.

5.7 Implementation phase: initial phase

At the beginning of the executive phase, the patient reduces eating and drinking more or less gradually, usually over the course of a few days, but sometimes faster or slower. A start is made with general physical care (depending on the patient's physical condition) and oral care. Physical care and oral care are continued in the middle and dying phases. Good guidance for relatives and good care for those caring for them are of great importance in all phases of the process.

5.7.1 Reducing food and drink

In many cases, eating can be stopped quickly or even immediately, especially if the appetite has already decreased significantly. The feeling of hunger (if present) generally disappears within a few days. The condition for this is that the patient does not consume carbohydrates (e.g. in fruit (juices) or soft drinks). takes.

There is no general advice regarding the period within which to stop drinking. Some 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) required for oral care. Still others continue to drink more than 50 ml of water every day, which means the process can take (much) longer than 2 weeks.

During this period, the patient can experience what it is like to drink little or nothing at all and whether this can be made bearable with good oral care. It may also become clear how strong her death wish is. Sometimes it appears that the patient reconsiders her decision to stop eating and drinking.

It is not known how often this happens. If the patient indicates doubts about her decision, it is important to discuss this and highlight the different sides of her initial decision by discussing the pros and cons. Relatives are involved in this conversation, unless the patient expressly 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. Ultimately, full physical care will be necessary in all cases. This is provided by nurses/carers, volunteers (in the hospice or at home) and/or loved ones. If the relatives take care of part or all of the care, proper instruction by the nurse/

caregiver is very important.

The patient's comfort comes first. In consultation with the patient, it is agreed what the wishes and expectations are with regard to care and/or nursing. The care plan records agreements about the manner in which care and/or nursing takes place (washing, dressing, changing the bed, products to be used (such as impregnated washcloths and care products) and, if necessary, changing positions).

During the preparation, a high-low bed has already been provided (where 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 ulcers or other skin problems, a specialized nurse can be consulted. See the national [Pressure Ulcer Guideline](#) and the [Smetten Guideline of Nurses & Caregivers in the Netherlands](#). Naturally, some routine nursing actions (e.g. taking temperature or blood pressure) are omitted.

5.7.3 Oral 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 complaints of dry mouth and feelings of thirst as much as possible. It is started at a time when the patient is not yet experiencing any problems. Initially, the patient will sometimes be able to take care of her mouth herself, but she will gradually become more and more dependent on others. If at all possible, relatives are involved in oral care, because they are often present with the patient most of the time. Good instruction is then required.

The mouth is thoroughly inspected at least once a day by a healthcare provider to detect oral problems at an early stage. This requires good lighting (flashlight), gloves and (wet) tongue depressors or gauze pads. The lips, buccal mucosa, tongue, floor of the mouth, gums and teeth or dentures are systematically inspected. An oral status score can be used if necessary.

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

- refreshing the mouth using:
 - a water nebulizer (small plant sprayer or eau-de-cologne bottle); three puffs contain approximately 2 cc of water (as often as desired);
 - half an ice cube, shattered and wrapped in gauze, on which can be sucked; this contains approximately 5 cc of water (as often as desired);

- licking a sugar-free popsicle;
- for bad breath: mouth spray with mint flavor or mouth spray with chlorhexidine, cetylpridinium chloride and zinc lactate (Halita®) (spray on the tongue 2-3 times a day with 3-4 puffs);
- stimulating saliva secretion by using sugar-free chewing gum or sugar-free sweets (provided the patient is still able to chew or suck);
- the use of mouth moisturizing products or saliva substitutes (especially before sleeping, to prevent dehydration of the mucous membranes when sleeping with the mouth open):
 - Biotene Oral Balance® gel or spray, as needed;
 - BioXtra® gel, spray or mouthwash, as needed;
 - Caphosol® solution 4-10x per day;
 - Saliva Orthana® gel or spray, as needed.
 Have your loved one check whether these products are reimbursed by your health insurance;
- rinsing the mouth with physiological saline (a level swab).
 - teaspoon of salt in a glass of lukewarm tap water, 4 times a day, more often if necessary) or 0.12% chlorhexidine; After rinsing, the mouthwash is spit out again. If the patient is no longer able to rinse the mouth, the mouth can be rinsed 4 times a day (more often if necessary) with physiological saline or chlorhexidine using a syringe. The mucous membrane of the mouth and tongue can also be wet with a moist gauze, a cotton swab or dental swabs;
- keeping the lips greasy with the help of Vaseline or lip cream (twice a day, more often if necessary);
- brushing the teeth with a soft, preferably electric, brush toothbrush (twice a day);
- cleaning between the teeth (interdental) using brushes, toothpicks or dental floss (once a day);
- cleaning the dentures. The dentures can (partly depending on the patient's wishes) initially be left in during the day, for reasons of appearance and also to make speaking easier. If

the patient no longer appreciates it or if there are oral problems, the denture is also left out during the day.

- brushing the tongue (if necessary, once a day); A soft toothbrush or tongue scraper can be used for this purpose.

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

Most of the required materials are not reimbursed by health insurance and are available at the drugstore.

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

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

For further information, see the [Guideline for Oral Complaints in the Palliative Phase](#) and the [Oral Care Guideline for care-dependent clients in nursing homes](#) of the Association of specialists in geriatric medicine.

5.7.4 Guidance for relatives

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

Signs of overload can be:

- stress reactions, such as headaches, insomnia, loss of appetite, tension, nervousness and depression; in severe cases there may be a negative cynical attitude, emotional lability, anger, verbal or physical aggression or aversion to the situation;
- use of (too) many sleeping pills or tranquilizers;
- increase in smoking and/or alcohol consumption;
- feelings of guilt or feelings of inadequacy;
- physical complaints, especially of the posture and musculoskeletal system.

Good information and instruction from relatives regarding the care are essential throughout the process. The loved ones must have the opportunity to rest or sleep (e.g. by deploying caregivers or volunteers at night) and (if desired) to also be able to escape from care and the home or institution during the day. to be able to leave. The basic principle in supporting loved ones is that the care provider anticipates problems that may arise sooner or later for the loved ones. To this end, regular discussions are held with relatives in which the following topics may be discussed:

- feelings about the patient's decision;
- their own role in the process;
- load and carrying capacity;
- the presence of the above signals;
- (dis)satisfaction with the care provided by healthcare providers and/or volunteers
- liars;
- need for (more) support;
- worry and fear of what is to come.

The spiritual counselor can also play an important role in guiding loved ones.

5.7.5 Care for those caring for them

Caring for a patient who consciously refrains from eating and drinking can also be stressful for caregivers and volunteers. Good information,

good communication between caregivers and volunteers, and optimal coordination of care, are essential to ensure that the process runs smoothly and to limit the burden on those providing care as much as possible.

During the process, attention must be paid to the emotions of all healthcare providers involved (including volunteers). This can be done by coming together at set times, for example every two to three days, and sharing experiences and emotions with each other. This can vary from a consultation between the GP and home care, to an extensive multidisciplinary consultation in the nursing home or hospice, in which the spiritual counselor can also be involved.

In a conversation after the death of the patient, the course of events and the emotions and questions that the process has evoked among the healthcare providers and volunteers involved can be discussed.

5.8 Executive phase: middle phase

The duration of the middle phase is variable. Depending on the severity of any disease present, this phase (with minimal fluid intake) usually does not last longer than 1-2 weeks. If the patient has not kept drinking to a minimum (< 50 ml/24 hours), it may take days or weeks longer before the patient dies. Furthermore, the duration 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 drinks little or nothing at all, increasing weakness and bedridden occur in this phase.

Relatives and/or caregivers are usually continuously present for physical care, oral care, support and guidance, and also to prevent the patient from falling when attempting to get out of bed.

This period can be very important and enriching for the loved ones on the one hand, but also very stressful on the other. Support and guidance

of loved ones are of great importance. This can also be a stressful period for healthcare providers. They also need attention.

Increasing dehydration will occur in this phase. Various complaints and problems may occur, such as thirst, dry mouth, problems with micturition and defecation, pain, nausea/vomiting, restlessness, confusion and delirium. If during the course of the process there is an untreatable (refractory) symptom that causes unbearable suffering, intermittent or continuous palliative sedation can be used.

The above aspects will be discussed below.

Naturally, other complaints and problems can also occur in this phase, especially if they were already present before. For information about 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 can have both a favorable and an unfavorable influence on a number of existing complaints and problems or (if not present) on the risk of their occurrence ([Guideline Dehydration and fluid administration in the palliative phase](#)).

Beneficial consequences may include:

- less urine production, resulting in less toilet use, a decrease in urinary incontinence and less need for a bladder catheter;
- less sputum production, resulting in less coughing;
- less vomiting and less diarrhea;
- decrease in peripheral edema, ascites, pulmonary edema or cerebral edema;
- less pain due to decrease in edema around tumor.

Adverse consequences may include:

- dry mouth and thirst;

- increased risk of urinary tract infections;
- dry mucous membranes;
- tougher mucus;
- constipation;
- accumulation of medication that is excreted through the kidneys and there due to a greater risk of side effects;
- greater risk of confusion and delirium.

5.8.2 Problems with micturition and defecation

Urine production will usually decrease sharply over time. As long as the patient is able to do so, use of the toilet or potty chair is preferred. When the patient is (or has become) completely bedridden, you can choose to use:

- one pot or urinal;
- incontinence material or a mat;
- a condom catheter (for a man) or indwelling catheter.

For further information about voiding problems, see the [Urogenital Guideline issues](#).

With regard to defecation, a one-off phosphate enema may be considered when the patient stops eating and drinking. If no defecation occurs in the future, 10 mg bisacodyl supp. are considered every other day. Defecation usually occurs within 30-60 minutes after administration. If this does not happen, a rectal examination can be performed. If there is fecal impaction, a phosphate enema is given or, if necessary, the stool is removed digitally (with the finger) by the nurse or doctor.

For further information, see the [Constipation Guideline in the palliative phase](#).

5.8.3 Pain

In some cases, the patient is already using painkillers as maintenance treatment when she decides to give up eating and drinking. Naturally, pain relief is then continued, with the dose being adjusted (and if necessary adjusted) based on the intensity of the pain. If the medication is administered orally, sooner or later conversion to another route of administration is appropriate (see table 5.1). The use of a pain score or observation list is recommended.

Paracetamol can be administered rectally, usually in a dose of 1000 mg supp 3-4 times a day. NSAIDs (diclofenac and naproxen) can be administered as a suppository (in the same dosage as oral), but their use is not recommended. The reasons are the usually advanced age of the patient and the fact that it is likely that kidney function will deteriorate in this phase due to dehydration, which increases the risk of side effects (stomach complaints, 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) chance of side effects. Therefore, fentanyl patches are preferred, in combination with a laxative, for example bisacodyl supp.

Slow-release morphine and oxycodone can be administered rectally, but this route of administration is not preferred for several reasons.

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

During maintenance treatment with opioids, medication should be available for the treatment of breakthrough pain. Because these are incidental administrations, the objection to the use of morphine no longer applies.

For the treatment of breakthrough pain:

- immediate release morphine:
 - oral (drink) or rectal (both in a dosage of 1/6 of the oral daily dose; when using fentanyl transdermally, 1/6 of the corresponding oral daily dose of morphine is given, see table 5.2);
 - subcutaneous or intravenous (also 1/6 of the daily dose);
- immediate release oxycodone orally (tablet or oral solution) or subcutaneously/ intravenously (both also in a dose of 1/6 of the (converted or not) daily dose);
- fast-acting fentanyl. For all fast-acting fentanyl preparations, start with the lowest dose (irrespective of the dosage of the maintenance medication).

For the opioid conversion table, see the [Pain Guideline in patients with cancer in the palliative phase](#) in the 'Summary, General' section.

Even if the patient initially has no pain, painkillers are prescribed and administered independently. Pain can occur during the process due to lying down for a long time and sometimes due to skin problems. Initially, paracetamol suppositories will suffice (1000 mg supp. up to 4 times a day if necessary). If the oral and rectal route of administration is not possible or undesirable or has insufficient effect, fentanyl 100 µg sublingually or 50 µg intranasally, immediate release morphine (if necessary 5-10 mg rectally, if necessary 2.5-5 mg subcutaneous or intravenous) or immediate release oxycodone 2.5-5 mg subcutaneous or intravenous). If the effect is insufficient, the dosage is increased.

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

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

5.8.4 Nausea and vomiting

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

Initially, metoclopramide 10 mg supp. 3-4 times a day. or subcutaneously, or haloperidol 0.5-2 mg (5-20 drops) twice daily given buccally or subcutaneously. If the effect is insufficient, levomepromazine 6.25 mg is given subcutaneously or via the cheek pouch. Dexamethasone (as an anti-emetic) is in principle not given because of its appetite-stimulating effect.

For further information, see the [Nausea and vomiting in the palliative phase guideline.](#)

5.8.5 Agitation, confusion and delirium

Unrest can be caused by:

- symptoms that are not sufficiently controlled (e.g. pain or shortness of breath);
- full bladder or full rectum;
- bladder cramps with bladder catheter;
- overstimulation, for example due to too many people at the bedside;
- angst;
- side effects of medication (e.g. metoclopramide, dexamethasone or benzodiazepines);
- withdrawal from medication (particularly opioids, corticosteroids, benzodiazepines), alcohol, nicotine or drugs;
- delirium.

Delirium is characterized by:

- disturbances in consciousness (reduced awareness of the environment);
- disturbances in attention (a reduced ability to direct, direct, maintain and shift attention);
- change in cognitive functions, such as disorders memory, in orientation in place and time, and in thinking and perception (delusions and/or hallucinations).

The symptoms develop over a short period of time, vary during the day and are often most pronounced at night. Delirium may be accompanied by restlessness (hyperactive delirium) and/or apathy (silent delirium).

Delirium is often preceded by signs, such as disturbances in the circadian rhythm, bad dreams, concentration and attention disorders, disorientation in time and place, hypersensitivity to light and/or sound, suspicion or hallucinations.

Delirium occurs relatively often in patients who consciously stop eating and drinking as a result of:

- the often advanced age of the patient;
- dehydration;
- medication (particularly opioids);
- the impending death.

Delirium is a very unpleasant experience, not only for the patient himself, 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, caregivers and loved ones are of great importance. **The Delirium Observation Scale (DOS, see [Delirium Guideline in the palliative phase](#))** can be used. A score is drawn up 3 times per 24 hours based on observations by the nurse or caregiver. With a low score, delirium is unlikely. A score of 3 or more is consistent with delirium, but is not indicative of it. The diagnosis is made by a doctor based on the clinical picture.

Delirium in the final phase of life can sometimes be prevented by:

- providing landmarks (clock, photos in the room, acquaintances) faces at the bedside);
- avoiding too many stimuli (sound, images) at the same time;
- the use of glasses and/or a hearing aid;
- no sudden discontinuation of opioids, benzodiazepines or corticosteroids, especially at high doses and/or long-term use;
- sticking a nicotine patch on patients who smoke a lot to have.

The best treatment for delirium is treatment of the triggering factor(s), e.g. change of medication, treatment of infections (e.g. a urinary tract infection), treatment of urinary retention or correction of dehydration. However, in a patient who has stopped eating and drinking, treatment of the triggering factors is often not required.

If necessary, a urinary tract infection can be treated with a single administration of fosfomycin. In case of urinary retention, a catheter is inserted. If opioids are the cause of the delirium, opioid rotation (replacing one opioid with another) or sometimes reducing the dose is an option.

In the context of the patient who has stopped eating or drinking, the special situation may arise that the patient requests fluids in her delirium (Quill 2018-1). In that situation, the patient will usually be incompetent with regard to the decision to start drinking again. If the incapacitated patient asks for something to drink insistently and repeatedly, a difficult situation can arise. On the one hand, it can be very difficult to refuse this request, on the other hand, the loved one or care provider may want to adhere to the agreements made with the patient when she was still competent. In such a situation, one can fall back on agreements made about this in the preparatory phase and/or on the advance directive (see section 5.6.4).

It is crucial that healthcare providers, especially when a difficult situation arises, do not simply violate the agreements with the patient (who then exhibits unconscious behavior), adjust the policy and provide fluids. The patient cannot achieve her own desired goal by providing fluids. Therefore, prevention and treatment of delirium through the non-drug methods described below

measures are important, as well as an anticipatory policy with 'if necessary' medication policy in case of restlessness and delirium.

Non-drug measures are an important part of treatment. These are the same measures as those mentioned in prevention. The goal is to create a calm, stable and safe environment. The continuous presence of someone you know can play an important role in this. Explanation to loved ones about the situation and how to deal with it is important. It is important to communicate calmly and clearly with the patient and not to contradict delusions or hallucinations. It should also be emphasized that there is no point in speaking to the patient or making appointments. In many cases, the patient must be considered incompetent at the time of the delirious symptoms. Extensive protective measures against climbing out of bed and falling (such as side rails and restraints) often have a counterproductive effect and are only taken in extreme cases and only after explanation and permission from the representative.

For drug treatment, reference is made to the [Guideline Delirium in the palliative phase](#) (www.palliaweb.nl) and the [Delirium Guideline adults and the elderly](#) of the Dutch Association 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 experiences unbearable suffering due to one or more symptoms that cannot be controlled (otherwise) (so-called refractory symptoms), palliative sedation can be considered (see section 2.8 and section 4.5).

Reviews mention the (proportional) use of palliative sedation as an option during the BSTED process (Gruenewald 2018, Den Hartogh 2020, Lovers 2021-1, Schwarz 2009, Wax 2019). The committee sees no reason why palliative sedation should not be used during the BSTED process 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 ([Guideline for Palliative Sedation](#)). For continuous palliative sedation, an estimated time until death of a maximum of two weeks is a condition. 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. Intermittent sedation can be used as a first step, especially during difficult and restless nights (despite sleeping medication).

A patient who has stopped eating and drinking often suffers from exhaustion and/or delirium, but sometimes (also) from thirst that persists despite good oral care. This is a refractory situation for two reasons. Firstly, the patient has not given permission to provide fluids or to administer artificial fluids (and therefore the symptom is untreatable). Secondly, fluid intake leads to a very undesirable extension of life for the patient, which in this context can be considered an unacceptable side effect.

The [Palliative Sedation Guideline](#) furthermore indicates that as existential

suffering can no longer be alleviated by, for example, conversations or spiritual support, this suffering can also be refractory. Existential suffering can therefore be part of refractory symptoms that lead to unbearable suffering for the patient. In the context of a patient who has consciously stopped eating and drinking, existential suffering can also play an important role. In many cases, the use of palliative sedation during the BSTED process involves a combination of restlessness or delirium, exhaustion, thirst and existential problems, which leads to unbearable suffering.

Continuous palliative sedation can and should only be used if the patient has shown that she consistently refrains from eating and drinking. A period of at least a few days during which the patient has had little or no drinking is a requirement for this. In that case, the condition of an estimated period until death of a maximum of two weeks is met. If there is doubt about the consistency of the decision to refrain from eating and drinking, continuous sedation is not (yet) indicated.

For this reason, continuous palliative sedation is not immediately initiated when the patient actually stops eating and drinking.

Palliative sedation is applied proportionately. This means that the aim is to achieve the level of reduction in consciousness that is necessary and sufficient for the desired level of symptom relief. The measure of the effect is the comfort of the patient and not the degree of loss of consciousness. In some cases, a mild degree of loss of consciousness is sufficient to relieve suffering (superficial sedation). In that case, the ability to communicate is retained. In practice, deep sedation is often used, which means that the ability to communicate is lost.

In principle, permission from the patient or (in case of incapacity, for example due to delirium) from the representative is required for the use of palliative sedation. In acute situations (if the patient is incapacitated)

condition and there is no time to ask the representative for permission), palliative sedation can be used without permission. However, this situation will almost never arise in the BSTED process.

It is important to emphasize in the information provided to patients and relatives that palliative sedation does not hasten death, provided it is applied in accordance with the guideline.

For the treatment schedule and dosages of medication to be used, see the [Palliative Sedation Guideline](#). If a patient has already been treated with opioids and/or antipsychotics, this medication is continued, but only to combat pain, shortness of breath or delirium. In case of pain or delirium, levomepromazine can be used early in addition to midazolam. In case of pain, the opioids are then continued; in the event of delirium, haloperidol can then be discontinued.

5.9 Executive phase: dying phase

The dying phase is the phase immediately preceding death, in which death inevitably presents itself. The patient is expected to die within days. The course of the dying phase of patients who have consciously stopped eating and drinking is essentially no different than that of patients who die as a result of a life-threatening illness.

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

Signs of impending death include:

- severe fatigue and debilitation, leading to complete bedriddenness
heath;

- reduced urine production;
- fast, weak pulse;
- cold-feeling, sometimes cyanotic extremities and development of corpse stains;
- pointed nose (the skin over the nose and cheekbones tightens);
- reduced consciousness and ultimately often complete loss of consciousness are;
- increasing disorientation, sometimes accompanied by hallucinations and terminale onrust ('terminal restlessness');
- audible, rattling breathing;
- 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 begun, but also the healthcare providers and volunteers involved. During the conversation with relatives, the following topics are discussed:

- their reactions and emotions following the dawn of the dying phase;
- what complaints and problems can be expected and how this is dealt with; it is noted that rattling and Cheyne-Stokes breathing often occur before death, but that the patient does not experience shortness of breath;
- keeping vigil at the patient's bedside;
- desired rituals, appropriate for philosophy/religion and culture;
- desired/necessary (extra) deployment of healthcare providers or volunteers;
- what to do if the patient has died.

The physical care of the patient and the treatment of symptoms are not essentially different from the care and treatment as described in the middle phase. Attention to good oral care is even more important than in the previous period, because the patient is no longer able to do it himself and often lies with his or her mouth open for a long time.

The chance of delirium in the dying phase is greater than in the period before. Early recognition of the (symptoms of) delirium and treatment are essential. A possible pitfall here is the occurrence of restlessness in a patient being treated with opioids.

It often happens that the restlessness is interpreted as a result of insufficiently controlled pain or shortness of breath, and that additional opioids are therefore given and/or the dosage of the opioids is increased. In many cases, such restlessness is a manifestation of terminal delirium and giving or increasing opioids will only increase the restlessness. Consideration should be given to reducing the dosage of the opioid (if there is room for this) or to rotate to another opioid. Furthermore, in case of restlessness, the possibility of urinary retention or constipation should always be considered.

For further information, see the [Care in the dying phase guideline](#).

The death of a patient who has consciously stopped eating and drinking is considered a natural death. The death papers are completed in the usual manner, with 'stopping eating and drinking' being stated as the direct cause of death. There is no reporting obligation and the municipal coroner does not have to be involved.

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

6. EXPERIENCES OF PATIENTS, Relatives AND PROFESSIONALS

This chapter discusses the experiences of relatives and care providers who have dealt with a patient who consciously stopped eating and drinking.

6.1 Interview with Hilde Brontsema

Source: Barbara Beukering. 50 ways to say goodbye. You can only do it once. Unieboek, Het Spectrum, Amsterdam November 2021. With permission.

You can only do it once

"When I came to say goodnight, he said: 'Push that pillow on my head.'"

Piet Brontsema no longer wanted to live with his chronic pain, but because the euthanasia committee could not help, he had to make his own orchestrate death.

Piet Brontsema (69, advisor on tackling unemployment) died on August 24, 2020 after he stopped eating and drinking. With Riet van Eindhoven (67, night nurse), who died on February 18, 2020, he had three children; Margot (45), Hilde (44) and Jelte (41). Hilde lives with Ynse, they have two sons, aged 13 and 10.

Hilde (44):

'At the age of 56 my father suffered a brain haemorrhage. After his rehabilitation, he was initially paralyzed on one side, he continued to have difficulty walking and his vision remained poor. He was very intelligent, and remained so, but he could no longer work. The biggest problem after the brain hemorrhage was his change in character. His emotions were greatly magnified; he laughed very loudly at jokes, he cried very quickly and he could become angry beyond reason. Then he called my mother a rotten fish. She tried very hard to keep the relationship going, but it didn't work.

She felt guilty about leaving him, but all three of us children supported her choice. My mother always had a good relationship with my father and she also continued to help him.

While I was on a ski vacation with my family over spring break, my brother called to say that my mother had died in her sleep. She did volunteer work and never missed it. The ninety-year-old woman she was caring for had called her children to say that my mother had not shown up. Her children came to the door and when my mother didn't answer the door, they called 911. The police found her, she was dead in bed. My mother never had anything, she was a very healthy, vital woman. It was a huge shock. Afterwards I often dreamed that I had to say to her: 'Yes, but you are dead'. Because it came so unexpectedly to me, I thought she didn't know it yet.

A month and a half after my mother died, my father started complaining of headaches and pain in his leg, followed by the statement that he no longer wanted to live. We didn't know whether to take it seriously, but his death wish became more and more emphatic. I suggested he come live with us for a while. I thought the comfort of a family would do him good. Eating well every day and being treated to something, he also appreciated that. When he was playing a game with the children in the evening, there was no depressed man there. But the death wish remained. He repeated it every day: 'I'm in too much pain, I can't do it anymore.' When I came to say goodnight to him, he would say, "Push that pillow on my head."

He registered with the Expertise Center for Euthanasia. Before I could support him in this, I wanted to know what caused the physical pain. Only if a doctor could say that nothing could be done about this pain would we help him, my sister, brother and I agreed with him. We don't want to be left with a feeling of guilt. When he left me, there was a place in the Winschoten rehabilitation center. After several investigations, it was said that a traumatic experience like death

from our mother can cause physical pain in a patient who has had a cerebral hemorrhage. The neurologist tried to relieve the pain with medication, but there was no improvement.

Although they were very respectful at the euthanasia clinic, their final conclusion was that they could not help him. He suffered unbearably, we did not pressure him and his desire to die was consistent.

But they couldn't make a good judgment about whether it was hopeless. They said they might be able to help him in six months, but not yet. My father thought that took too long. The euthanasia doctor explained that there were two other options: stopping eating and drinking, or the last pill.

My father called on Tuesday and said firmly: 'I'm going to stop eating and drinking'. The three of us immediately went to him. The doctor at the rehabilitation center was willing to guide him through the mortification process. He didn't want to go home anymore. We still tried to discuss things; who he still wanted to see and whether he had any wishes for the funeral. It didn't matter to him anymore. He had made a decision and you could see that peace had come over him. He was cheerful, he was ready, this was what he really wanted. My sister made another attempt to have a conversation and asked if there were things in his life that he wished he had done differently in retrospect. "I would have liked to exercise more," he replied. Nothing of substance came out. He was also not interested in a last supper. He used to be a foodie but now none of that mattered. He immediately stopped eating and drinking that Tuesday, he only had one goal.

The week passed very quietly. At one point my father called saying he wanted to take another ride with the family. He wanted to go to the Punt van Reide, at the very top of Groningen, where he often cycled with my mother. On Sunday morning we were all there; my brother, my sister and I with our families. My father talked a lot on the way

yes. We took a photo where we were all standing up, my father in a wheelchair happily standing in the middle. Afterwards he wanted to go for a drink somewhere, he fancied a spa red with a lemon. We reacted in shock: 'Are you going to drink?' "No," he said, laughing, "I'll just take one sip." It wasn't loaded at all, he was very happy with it.

The next morning he was barely accessible. It was agreed that if the doctor saw that he was nearing the end, he would be put to sleep. To administer four hours of sedation. In the afternoon the doctor came to check the pallia sat in bed at the end of his bed and my sister sat next to the bed by his arm. I said to my sister, "If we put him on a feeding tube now, could we bring him back to life?" My sister replied, "I do think there is a point of no return." She squeezed my father's arm and said, 'No, Dad, we're not going to do that.'

While we were laughing very loudly, my father breathed for the last time. We thought it was a joke, very typical for a Brontsema.

In retrospect, I'm very glad he chose this way to die. He did it all himself and thus spared us.

Moreover, I now know how valuable it is to be able to say goodbye.

To be able to say: 'I love you, just let it go, go'. He was not alone. I would have given it so much to my mother too. I would have loved to say goodbye to my mother and thank her for everything she has done for me.

6.2 Mrs. Van Ark talks about the special farewell of her husband

With thanks to and permission from Erik Dierink, nurse specialist, member of the Consciously Stop Eating and Drinking Guidelines Committee.

a healthy man, a Marine through and through. A man who never complained. This is how Mrs. Van Ark (89 years old) describes her husband who died last summer at the age of 91. His wish was for that long

possible to live together at home. This suddenly came to an end when he had an unfortunate fall at home. Mrs. Van Ark, son René and granddaughter Maaïke tell how they experienced the time that followed.

What dominates is admiration: “Until the end he was determined about the way he wanted to say goodbye.”

After his fall, Mr. Van Ark received a new hip. “After his operation, he was transferred to a nursing home in Enschede,” says Maaïke. “I wanted to get grandpa closer, so that grandma – who lives in Hengelo – could go to him. This finally worked. He was able to recuperate at the TMZ location Het Hof in Hengelo.” René nods in agreement. “At that moment he really went for it. Even though he also had untreated COPD, an incurable lung disease. He wanted to recover from the hip operation and live at home again.” Mrs. Van Ark nods: “He wanted to experience our 70th wedding anniversary on March 7, 2019. He held on to this and he saved it.”

Turning point

Shortly afterwards, during his rehabilitation period, things went wrong. Maaïke: “He leaned over from his wheelchair to grab something. He fell on his chest and broke his sternum.” Mrs. Van Ark remembers it well: “The combination of recovering from hip surgery, the untreated COPD and the broken sternum caused a lot of shortness of breath and pain. It was immediately clear to him that the situation had become hopeless. Due to the unbearable suffering, he made his request for euthanasia known. He wanted to use the advance directive that he had drawn up in the past because of COPD.”

“The situation had become hopeless”

Wish

Mr. Van Ark made this euthanasia request known to the care team.

Erik Dierink, nurse specialist at TMZ. Erik: “From the moment he came to our department, we immediately clicked. When I was in the department to visit, I regularly visited him

came by to see how he was doing.” Maaïke: “Grandpa pushed his boundaries out of love, but after his fall you saw that he suffered and no longer had a quality of life. He knew he couldn't go home to be with Grandma anymore.

Getting out of bed was also not possible and too much effort.”

Erik nods. “He indicated that he wanted to make use of his advance directive as soon as possible.”

Conversations

But then it turned out that the general practice had just closed for the summer holidays. Erik: “Taking over a euthanasia request by one

Another (GP) doctor requires some time, because there must be a treatment relationship and a bond of trust. This would take time, which the gentleman did not want to wait for. We had many conversations then; with the gentleman, his family, the geriatric specialist and the care team. We discussed all the options with each other.

Ultimately, the gentleman decided to give up food and drink completely. The medication was also stopped.” René: “He was happy that he was in control.”

Dates

Erik: “We carefully discussed all scenarios, put agreements on paper and agreed how we would combat any inconveniences. It is very important to manage this properly. The care team often visited him to inquire and assess his situation. It went very quietly, partly because the gentleman was very steadfast.

Mrs. Van Ark fully supported her husband's decision. “He was determined, confident and powerful. He told me, 'girl, I haven't been this happy in years.'”

Special days

What remained were four special days. Mrs Van Ark: “I think he also experienced it that way. He lay in bed and enjoyed all the visitors that came by. It was wonderfully clear.” René agrees: “He

even chose his own funeral card, with swallows." Maaike also believes that her grandfather was able to say a full farewell to everyone who was dear to him, such as his children and grandchildren.

"We were also able to capture this in beautiful photos and videos that are now invaluable. As a close-knit family, we really enjoyed these last days. He died on July 28."

"He still chose his own funeral card"

Grateful

To this day, Mrs. Van Ark and the Erik family and the care team are extremely grateful for the guidance (day and night). "We were well guided and it went very nicely and peacefully. When I think back, it wasn't sad, it was beautiful. My husband and I have had a wonderful life together and we are of age. My children and grandchildren support me. My husband urged me: take care of yourself and enjoy." Then Mrs. Van Ark looks at Erik. "It was always his wish that Erik would come to our home again. And look now." She is beaming. "This wish has yet come true."

6.3 A completed life

Source: Practical issue. Medical Contact No. 39, September 29, 2022. With permission.

I visit him in mid-December. He is well into his 90s, well-spoken and has worked as a general practitioner in the region for half his life. He has had discussions with his own GP about the end of life. His life is complete, it may be finished.

However, he is relatively healthy and there is no medical basis for euthanasia. As a geriatric medicine specialist, I work with the patient's GP and have been asked to think about the current situation situation.

So there we are, in the presence of one of the children, in his spacious apartment. He talks about his life, his studies as a doctor and his graduation just after the Second World War. He works as a general practitioner

I did it with pleasure and also had a nice old age. Some time ago he fell and underwent surgery. He says he is done with life, he considers it completed, but death does not come. We discuss euthanasia legislation together. He understands that there are insufficient grounds for euthanasia. "But I'm done with it anyway, doctor."

I explain to him that stopping eating and drinking would be an option. He is immediately interested. 'Could that also be possible within the hospice?' He is relatively healthy and there is no medical basis for euthanasia.

A few weeks later he was admitted to our hospice. He last ate and drank the night before. We have made good agreements: do not ask the gentleman if he wants to eat and/or drink, do not offer anything, but if he wants to stop himself, this is possible. In case of terminal delirium and/or other refractory symptoms, he wants palliative sedation. During his stay he meets several hospice volunteers with whom he was involved as a general practitioner during their birth.

Beginning and end come together.

He was admitted for exactly a week. He was not hungry and/or thirsty, partly due to excellent oral care in which keeping the oral mucosa moist is paramount. Initially, he sometimes took a time-out with midazolam, for example to get through the nights a little better (intermittent sedation). During the last three days he was continuously given palliative sedation because he was mentally exhausted and wanted rest. He died peacefully, surrounded by his loved ones.

In conversations during his stay with us in the hospice, this former colleague gave a message.

'Make more publicity about the possibility of consciously stopping eating and drinking under supervision. This is a good option, especially for elderly people with such a clear death wish if euthanasia is not an option or is not desirable.'

So it happened.

6.4 Interview Eva Bolt

Source: Interviews with patient, loved one and GP in the context of the research project 'Consciously stop eating and drinking (2020-2022)'. By Eva Bolt, GP researcher at the Amsterdam UMC.

Mr. B was a 92-year-old widower with an optimistic and reserved character. He was socially active, but noticed that he could do less and less. He said: "I have completed my life and I want peace. I have a beautiful life now. But I would rather leave, so that the children can still see a father who is still somewhat the image of a father they know."

Mr. B understood that he would not be eligible for euthanasia. He read in an NVVE magazine about consciously stopping eating and drinking and decided that that was the most humane way. Although he remained a bit angry that he couldn't just get an injection.

When he told his family about his intention to stop eating and drinking, they were shocked. They didn't see it coming and had a hard time understanding his decision. His daughter asked him: "why are you doing that, you are fine, you are healthy?" and later said: "Of course you try to do everything you can to persuade him." Ultimately, his children accepted that he really wanted this.

Mr. B postponed the moment a bit due to holidays and a death in the family and then stopped eating and drinking. He was supported by his children, home care and the GP. The doctor had discussed with him and his family in advance that he would gradually become drowsy and that it would take 7 to 14 days.

The first week after Mr. B had stopped eating and drinking, it was easy. He was cheerful and enjoyed the visits he received from his family. Mr. B had gotten the idea that after about 5 days his kidneys were to fail, he would become intoxicated and could be sedated. This was disappointing. After 5 days he was still fully conscious. However, he became tired and suffered from thirst. He therefore rinsed his mouth regularly. After a week, during which he hardly deteriorated, it turned out that he was regularly swallowing this water, as well as wet washcloths for

pinched his forehead above his mouth. He got the washcloths next not anymore.

Those around him also sometimes had difficulty in not giving him anything to drink. He had instructed his children: "If I ask for food and drink, even if I act ugly, even if I swear, even if I stand on my head, you are not allowed to give it to me." When he actually went to ask for water, his daughter told him with tears in her face: "No, Dad, I promised you, I wouldn't do it."

A home care worker had more difficulty with this and clearly wanted to continue to give him the opportunity to repent. She indicated that it was not stated in black and white anywhere that she was not allowed to offer him a drink. The GP visited almost every day and noticed that it was becoming increasingly difficult for the children. They also thought that it would be over after 1, at most 2 weeks. After 10 days, Mr. B increasingly confused and somewhat delirious. He even tried to suffocate himself with a pillow. The doctor gave him haloperidol and midazolam nasal spray, so he slept for several hours each time. When he woke up again, there was unrest, both for him and for the children, who remained closely involved. The GP wanted to start continuous palliative sedation on the 11th day, but needed the specialist home care team for a pump. However, they judged that there was no refractory symptom and that they could not yet start a pump.

The GP accepted this, but it was a big disappointment for the children. The GP also felt that the care was inadequate because he could not make him comfortable enough. Continuous palliative sedation was finally initiated on the 15th day and he died two days later.

Looking back, the GP believes that he would have liked to have read more thoroughly. Then he could have better warned the patient against excessive fluid intake and better prepared the family for the development of unrest. But the daughter describes afterwards: "It was not an ordeal. It is a very valuable experience. That you can grant your father's last wish in this way, no matter how contradictory it is."

6.5 'He really went to death happy and satisfied'

Source: By Rolf Bosboom. Algemeen Dagblad Saturday September 25, 2021.

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Michiel and Gijs Haak helped their father Floor die

Floor Haak from Vrouwenpolder was sure he wanted to die. He asked his sons to help him with this. Michiel cared for his father for thirteen days, until the moment came. Gijs filmed everything for a moving documentary. "This was a godsend for our father, but it was also very special for us."

At the beginning of 2019, Michiel Haak received a call from his father. "The time has come," is his message. "I'm ready now." 86-year-old Floor Haak thinks it was nice. He consciously chooses death by stopping eating and drinking. It has to happen in his own house, beautifully situated just outside Vrouwenpolder.

Michiel and his brother Gijs are not surprised. "It was a process that took years and it also suited my father," says Michiel, two and a half years later. "This was exactly what he wanted. I don't know if I would ever do it this way myself. But if someone really wants to get out, then I think this is nice. It's like an animal that feels it can't go any further. It lays down somewhere in a deserted place and waits to die. I had no doubts whatsoever about helping him with that."

In mid-February 2019, the entire family came together in Vrouwenpolder. "We started the next day. He was really ready. To be able to do this, you have to be very disciplined. And he was, until the end. That's why I knew he would succeed. From the first day he really didn't eat and only drank very small amounts. He occasionally had some ice cream to combat his dry mouth. He enjoyed that."

'My father sometimes called himself a rebel'

The brothers describe their father as a 'thinker of difference'. "He sometimes called himself a rebel. He avoided the beaten track and believed that you should approach everything in a playful way. It was a sport for him to look at things differently."

But there was also war trauma. "Both his parents were arrested and never returned. He was twelve years old at the time. That marked him. He believed in a better world, but later lost faith in the feasibility of life and society. He began to oppose health care and the school system. He found it all horrible, just like the way we want to keep people on their feet endlessly and deal with death. He believed that you should let nature take its course: life is beautiful, but death is part of it."

Vrouwenpolder

In 2002, Floor Haak – whose wife died early – moved from Amsterdam to Vrouwenpolder, the place with which he always had a warm relationship. "He felt less and less at home in the world and gradually withdrew. The entire development of society was not for him. He didn't have internet either. He was actually no longer of this world. He watched the news and believed it, although he did follow football. He saw Studio Sport until the last moment."

Life became increasingly difficult for him. "Mentally he was still very good, but his body became more and more of a burden. He had a lot of pain in his hip. He could have had surgery for that, but he refused. He didn't want a knife to come into his body. He tried to ease the pain with massages, vitamin pills and exercises, but his self-reliance was eventually put to the test. It took him a whole day to get up, eat something and take care of himself. But he didn't see himself in a nursing home, or being cared for by us. He had been out of society for too long and lived, with all his rituals, too much in his own world."

Directed ending

The conversations increasingly turned to an orchestrated end of life.

“To make it a bit more concrete, I gave him the book *Uitweg* by the psychiatrist Boudewijn Chabot,” says Michiel.

“Three methods are described there. He thought all three were terrible, but then he started to think about it. Ultimately, he decided that quitting food and drink suited him best. That is the most natural way, he said.”

“The advantage is that you do not need approval from doctors.

At the same time, it is not something you just do. I think it is important that you know very well what you are getting into. You must arrange the care properly and have guidance from your doctor. My father's was fantastic. He has been very important to the entire process.”

Michiel, who works in psychiatry, declared himself willing to care for his father during the trial. “He was very relieved by that. I think it also gave him peace, because from that moment on he knew for sure that there was a way out. Afterwards he spent a few months doing all kinds of things that he still wanted to do. Then he called and said: it

the time has come.”

Message to the outside world Floor

Haak asked Gijs, an experienced filmmaker, to record his last days. “His death was also a kind of statement for him: his message to the outside world. I thought it was interesting to film that, although at that time we didn't know at all whether we would do anything with those images. We just set up a camera and let it run.”

Because of the recordings, Gijs was also in the house in Vrouwenpolder during the entire process. “That was not the intention initially. I would just be at home in Middelburg and come by every now and then. Then it would have been a completely different experience for me. Looking back, I am very happy that it happened this way.”

Michiel initially had difficulty with the film plans. “I find caring for and the death of your father something very intimate. For me, that doesn't need publicity. But my father wanted to show people who struggle with the same things he did that this is an interesting way to die. Gijs also said: you don't notice anything from the camera. That was right. And it was very nice that he was there too. In the end it turned out very well.”

Mourning envelopes

On Monday February 18, Floor Haak stopped eating and drinking. “He was still very active for the first seven or eight days,” says Michiel. “He was mainly busy writing letters and answering mail. He also wrote his own funeral envelopes, sometimes with a personal message on the back. He wrote to an old aunt, who also longed for death: 'Now it's your turn.' She died on the day of his funeral.”

“I thought it was very nice that the three of us were here all this time,” Gijs adds. “We have never been together so intensively since the death of our mother.” Michiel: “He still enjoyed life and wanted to see everything: the tree, the birds, nature. Miraculously, the weather was glorious for two weeks. We had the doors open in February and he was lying there in the sun. The whole situation had something absurd, but at the same time it was magically beautiful.”

Their father remained headstrong until the end. For example, as his strength declined, he insisted on having bunches of flowers delivered to his regular hairdresser and to the woman at the local supermarket, who always put bread aside for him. Gijs: “He was very attentive and accessible to strangers, but less so to us. I did miss that. Ultimately, I think he did care about us, but wasn't very good at expressing it.

That sometimes continued to chafe.”

“There were many sides to his idiosyncrasy,” says Michiel. “For example, all objects had to be placed around his bed in a certain way and if you hung a tea towel incorrectly, you were told. He also had a CD of music he wanted to hear when he died, but the songs had to be played in a certain order. He was almost sometimes

maniacal, especially after he started living alone. What was initially playful became very rigid.”

Feyenoord-Ajax

Only after ten days of not eating did their father noticeably deteriorate.

“Until then he was in a very good mood. On Wednesday evening he followed the Feyenoord-Ajax cup match. After that it became more difficult. He got a bit confused, which often happens in such a situation. Then, in consultation with the doctor, we gave him morphine and a sleeping pill.

Still, he had a rough, unpleasant night that Thursday. Then he calmed down.”

After thirteen days, on Saturday March 2, Floor Haak, aged 86, died.

“He had chosen a good day for it. He hoped that all family members would be sitting around his bed. That worked.”

Say goodbye

Their time in the house made a big impression on the brothers. They make a comparison with euthanasia, where a loved one is no longer there from one moment to the next. Michiel: “A gradual process of two weeks is much nicer to go through. For our father this was one outcome, but it was also very special for us. Such a period also gives surviving relatives the space to say goodbye. Everyone has come by. He really went to his death happy and satisfied.”

They also took care of the funeral themselves. “We didn’t even have a funeral director. That’s doable. We also had time to prepare for that and it was completely in our father’s spirit. We laid him out in the shed with some cooling elements and later took him to the cemetery with a cargo bike. It was a really nice way to end it.”

Living is not a duty

The documentary has been released, entitled Thirteen Days. Michiel is very pleased with the result.

“Gijs has made a very beautiful film, which I can fully support. I think this can also help start the complicated discussion about completed life. My father’s idea was: show what happens when you stop eating and drinking and hopefully people will find it useful. We hope so too. Life is very beautiful, but ultimately not a duty. People should also be able to get out in a pleasant way.”

6.6 Widow, against all odds

Source: Annegreet van Bergen. My mother wanted to die. A personal and practical story about self-determination. Atlas Contact, Amsterdam December 2016. With permission.

Annegreet van Bergen describes in her book how the health of her mother continued to deteriorate after her father’s death, without any proven life-threatening illness. Her vitality continued to decline and she became increasingly dependent on

of others. Her death wish became more and more permanent. She talked to her doctor about euthanasia. She hesitated, but a consulted SCEN doctor¹⁵ found that she was not eligible for euthanasia. She talked to her daughter about a humane way to end her life. Stopping eating and drinking was also discussed. Annegreet van Bergen contacted her mother’s GP about this.

When I called the doctor, I briefly explained the situation and asked her to come see my mother. Then she could a. tell us whether she would even want to guide my mother and b. give an estimate of how long it would take my mother. We had that conversation more than a week before Christmas. The doctor said again that euthanasia was not an option, but

¹⁵ Before doctors can respond to a euthanasia request, they must request a second opinion from another doctor. This doctor is usually trained for Support and Consultation for Euthanasia in the Netherlands, SCEN.

stop eating and drinking. 'I just don't dare say how long it will take. Because even though you may not feel it, you're still pretty good. But I do want to help you. Stopping eating and drinking requires intensive guidance and that is not possible during the holidays. I can't help you until the new year.'

At the time I still thought that it wouldn't go that fast and that it would be good if we could think about it calmly first. But suddenly a lot of things happened and it seemed as if we were overtaken by the facts. Shortly after the conversation with the doctor, my sister from Enschede called. She was terribly shocked because our mother had lost a lot of weight in just a few days. She was in bed almost all the time and was barely able to allow home care.

We will never know exactly what happened. Had she more or less stopped eating and drinking because she developed swallowing problems again? Or was the deterioration related to the new painkiller she had been given for the vicious pain she had recently felt in her buttock muscle? Or had her HB levels fallen further?

I called. With difficulty I recognized my mother's voice. She said that whenever the phone rang, she always felt like her father was calling. A father who had died in 1966. She told a sister that it seemed as if he was standing behind her and that he said in Twente: 'Goa, ma, lie down.' Just like he had said when she was sick as a little girl. She told the neighbor that it seemed as if there were all kinds of people standing in the room

to say goodbye.

After a few days the hallucinations disappeared. A new phase began. Her mind became clear again, her voice steadier. But physically things went downhill quickly and she became increasingly unsteady on her feet. On Christmas Day she fell in the early morning.

P. and I brought a Tuscan meat pie and tutti frutti for Christmas dinner. A sister and followers were already there when we arrived. There was quite a commotion. My mother: 'I went crazy with my Rolls Royce. I took it too sharply.' That's how old a person can get

that he suddenly falls through his legs. She hadn't been able to get up again. She had had her alarm button on, but she thought it was too much of a commotion to use it. Someone will come, she had thought. And indeed. When no one answered the door, the lady from home care went to the neighbors and borrowed the key to the back door.

It was a strange Christmas dinner. My mother still came to the table, but had to be supported as she walked from her chair to the table. At the table, my sister and I were singing Christmas carols one minute, and wondering what to do the next. It was clear that our mother could not be left alone that night.

P. and I went to Zutphen, where I dropped P. off and grabbed my pajamas and toothbrush. When I got back to Enschede, the rest of the family left. 'What a hassle, huh? And all because of one pill,' my mother sighed. "I'm counting the days until the doctor gets back."

That first night I lay on a mat in the living room. But that was too restless. That wasn't because of my mother. He took an almost inaudible breath. But the refrigerator was freaking out and the heater was blaring.

It was sweltering. "Mommy won't exactly die in a climate-neutral way," we joked. Our normally frugal mother wanted the thermostat to be at least 23 degrees day and night. Otherwise she would be too cold.

The following days, my sisters and I took a different approach. We placed the referee's whistle next to her bed that she used to call us for dinner. Now she blew on it at night and then we helped her 'go to the toilet', as it is so neatly called in healthcare jargon.

'I'm so glad you're here. I couldn't have stopped doing this,' she said when we came back from the bathroom that first night. Later she was completely absorbed in herself, absorbed by the effort it took to go to the toilet, one step at a time behind the walker, with her daughter's back. My mother, who had always been a few centimeters taller than me, now barely reached my chin with the top of her head.

After a few days the toilet was too far and a toilet chair was placed next to her bed. She became increasingly frail. As if she just needed one more push. If

When I came downstairs and saw that she wasn't dead yet, I almost thought that was a shame. A sister had something similar. She had barely been able to control the urge to press a pillow over her head to the point of suffocation.

To be as prepared as possible, we informed home care immediately after Christmas of my mother's plans to stop eating and drinking. The person who coordinated the care arranged for home care to be provided four times a day with immediate effect and that the care would be further intensified after New Year's Eve. A safe with a secret code for the house key was placed behind the ivy at the front door. The women in home care did not often need that key, because one of us was with her almost all the time.

Because I wanted to know more about stopping eating and drinking, I looked for Boudewijn Chabot's thesis Auto-euthanasia. When I went into the local bookstore in Zutphen, I had high hopes of finding it there. Van Someren and Ten Bosch did not disappoint me. When paying, it seemed as if the saleswoman's gaze lingered on me a little longer than usual. Like 'will we see that again in the new year?'

Things were mixed with my mother in the last days of 2007. She often found herself nodding. But sometimes she was crystal clear and it was amazing how good her memory was. We were chatting with a girl from home care and I made my favorite joke, which was that my mother had improved considerably because of her marriage. Since then she was called Mrs. Van Bergen-van de Bult. My mother told me that a man with an even more dignified name had previously worked in her factory: Van Bergen, Bavaria and Hainaut. The girl now had someone in care with that name. My mother remembered that the man in the factory always sang. 'Then it must be the same, because this one is also such a singer.'

There was also singing in my head. Over and over again I heard Joan Baez: 'You know your mamma was born to die. All my trials, Lord, soon be over.' But that wasn't the case with my mother. Her trials were

still not over. Every now and then I cursed under my breath: how did people get into their heads to call the Netherlands 'euthanasia country'? In any case, she did not notice anything about a liberal euthanasia policy.

Unlike me, she cursed out loud. At times she was very angry and then she said that it had gone on long enough. And then for the umpteenth time: 'And all because of one pill.' In those days after Christmas I heard her curse more and more wholeheartedly than in all the years before.

Fortunately, she also had beautiful, satisfied moments. Then she said, "Oh, I'm so comfortable." Then she had just drunk a cup of tea, eaten a piece of Christmas wreath and managed to lay her head properly on the pillow. When I went to Albert Heijn, I gave her a kiss and said: 'It could be the last time.' But I also gave her a kiss every now and then.

'It's still possible now.' Then she smiled faintly.

So it finally became New Year's, her eighty-sixth birthday. No 'long will she live'. Only a few visits. It was especially the day after which she no longer had to count the days. The doctor would be back on January 2. In the evening I was alone with her.

'Mom, tomorrow I'm going to call the doctor. What do you want me to say?'

'What we discussed earlier. Because this is nothing.' She sounded very determined.

I read her something from Chabot's dissertation.

"Good," she said in a tone that made it clear she had heard enough.

'Shall I read something from the newspaper?' That seemed better to her. It became one interview with writer Marjan Berk who had won a million in the lottery. Birch is a 'portrait' for whom my mother always had a soft spot.

'Daddy had a chat with her again when we cycled past her house in the Weerribben and she was sitting in the garden.' This is how we rolled through the evening. Sometimes silently. Then talking again.

"Eighty-six," she said, shaking her head, "who would have thought?" And she changed into Twente: 'Tine van de Bult, what are you still doing here?'

Died within the framework of the law

It took me a long time to fall asleep. I felt like it was still the middle of the night when I heard the referee's whistle that second January.

Drunken in sleep, I stumbled downstairs. It was already morning. The digital alarm clock next to her bed showed a zero, an eight and two zeros.

Apparently my mother had been counting the minutes until she could wake me up.

'Gré, it's eight o'clock. You can call the doctor.'

'Oh no, Momma. Not now. Patience. I'm still sleeping. That phone call can wait a while. I'll be back in half an hour.'

I went back upstairs.

I had heard the flute in the middle of a terrible dream. I was sitting on the beach with a friend. She was dying and had a shriveled and shrunken body like my mother. Then I received the results of an examination from P. He only had two weeks to live. I had to tell him, but I couldn't find him anywhere.

After crawling back into bed, I slowly woke up and came back to reality. Knowing that my mother was waiting downstairs, I got up and went to her. Although it probably didn't matter what time I called, I still couldn't bring myself to keep her waiting any longer. So I called the doctor's office at a quarter past eight. I told the assistant what was going on. And there they were again: the broken voice and the tears. The assistant said the doctor would call back as soon as possible. That happened at half past eleven.

She promised to come by at a quarter past twelve.

Together with two daughters, my mother listened to the doctor. I sat there with my notepad. I noted, among other things, that the doctor advised me to immediately stop eating and drinking. That she expected – 'because you are still in reasonably good health' – that it would take two to four weeks. That good oral care (sucking on ice cubes or moistening with a plant spray) was important. That through the home

care mats and mattresses had to be installed to prevent her from developing bedsores. That if she became confused, she would be given haloperidol. (Not morphine; that would only add to any confusion.)

That a nurse would come every day and the doctor himself every other day.

When my mother asked whether she was in for an ordeal, the doctor replied: 'It takes time. The less you drink, the faster it goes. I will be generous with stimulants. But you have to do it.' At my request, she also prescribed sleeping pills. According to my mother, the first of her life.

I got the idea to ask for sleeping pills from Chabot's book. His thesis was discussed incidentally. The doctor had brought an interview with Chabot from Trouw as background information for us. Not without pride I showed her the thesis itself.

Ultimately, it would take eleven days before my mother died on Saturday evening, January 12, 2008. Looking back, I see five phases.

The first three days were more or less the same as the days after Christmas. 'I'm so afraid it won't work. I still feel very normal,' she said on the second day. There were some difficulties with someone from home care who had asked her if she wanted tea. Of course that was not the intention. We agreed that we would not offer her anything to drink. But if she asked for it herself, we couldn't refuse her either. At most we had to say that, in view of what she wanted, it was wise to drink as little as possible.

When the doctor came on Friday, the third day, and found her in an easy chair in front of the window, she had doubted whether my mother would still be able to do that on Monday. 'You probably won't get out of bed then.' With a slight triumph in her voice, my mother told us this.

The weekend was a kind of interim phase. The GP post had been informed of her plans. If the situation worsened, we could simply call for sedatives without the risk of a replacement trying to patch her up. This

a safety measure turned out to be unnecessary. She remained calm. Most of the time she was dozing. But when she was awake, she was as clear as ever. She did start to look eerily thin. She looked more like a woman from a fairytale book than my mother. Talking became increasingly difficult, mainly due to problems with her teeth.

That Sunday morning, my sisters and I made a schedule so that one of us would always be with her. Fortunately, we only had to make a schedule for the daytime. There would also be night care from Monday. That Sunday the four of us visited her one more time. Four crybabies and a mother. The daughters: 'You don't need us, but we respect your decision.' The mother: 'I have four very sweet daughters.'

The third phase lasted from Monday to Wednesday. As the doctor had predicted, she could no longer get out of bed. Sometimes she was still very witty. After drinking a sip of water, she said, "That won't kill me." And when a nurse apparently hadn't placed her head properly on the pillow: "You're wringing my neck."

Then again she was sentimental. "You're so sweet, you're so sweet," she said to the daughter who had obtained a bed arch from home care. She had once said that her mother, who was sixty when she died, eventually no longer applied anything to her skin. Now it was the same with her. She couldn't even wear a sheet. She was still covered by the bed arch, but the cover no longer rested on her body.

Sometimes she also became angry and rebellious. Then she cursed, "It's gone on long enough, for God's sake." And just to be clear, she added, "I'm a redhead. I'm not going anywhere. Not even to Dad. I'll just die!"

But on balance, good-naturedness still predominated in this phase. There was a coming and going of people. Not just the women in home care. Grandchildren, her brother and sister-in-law, neighbors and her best friend also came by. "It's strange to say, but I actually find it very pleasant," said one of my sisters. She was right. There was a relieved, pleasant atmosphere in the house.

In the meantime, it became increasingly difficult for my mother to stick to her decision. Not when she was lucid. Then she would sometimes ask for water, but then she would only take a tiny sip. However, she often became confused and apparently forgot her intention. Then she wanted to drink very often and in large gulps at the same time. The drops of haloperidol hardly helped to detangle her again.

Home care used words such as delirium and delirium to describe this confusion. I had also come across those terms in Chabot's dissertation. He defines delirium as a loss of consciousness with restlessness in movement. Delirium in itself is a fearful and exhausting experience, but in the case of fasting and thirsting to death, the loss of consciousness also prevents the person from consciously maintaining his or her choice to die this way.'

A little further, he writes that according to the guideline of the Royal Dutch Society for the Promotion of Medicine (KNMG), doctors may give palliative sedation (i.e. artificially put them to sleep) to a patient if he or she has a life expectancy of less than fourteen days.

Combining those two things, it suddenly dawned on me that there was a legal - and therefore acceptable to the doctor - way out that could put an end to all the trouble for my mother.

In the current situation, the doctor did not have to violate her conscience by estimating that my mother had at most two weeks to live. If she could knock my mother out, we'd kill two birds with one stone. My mother was able to persevere in her decision to stop eating and drinking. But it was just as important that she no longer had to notice anything about it.

Eureka!

Then we had to wait for the doctor.

"She won't have forgotten us," my sister and I said to each other when it was five o'clock on Wednesday afternoon. We called the practice. No answer. So we tried the doctor's office.

In a sense, that also resulted in a comical situation. According to it

menu we had to enter one for life-threatening situations. Although we were in a hurry, did this also qualify as life-threatening situations with my mother? We didn't think so. So we decided to wait our turn quietly. Once we were spoken to, we heard that the doctor had to make a number of visits before she would come to us.

When she was there, there was an unpleasant incident. We talked about the confusion that threatened to thwart my mother's plans.

The doctor then suggested that she sign a statement about what exactly she wanted. "Well I once did," my sister said. 'That was in the NVVE brochure. We asked you whether she should prepare such a statement. But you didn't think that was necessary.'

This seemed like the perfect moment to pull out Chabot's thesis. Very modestly I said that I didn't want to play doctor. 'But Chabot also talks about the risk of delirium in someone's mind

to fast unto death. I think you can and should combat her delirium. If I read page 190 correctly, I understand that you can now give her palliative sedation without any conscience or other objections.

Because she won't live longer than two weeks, will she?'

The doctor took the thesis from me. She sat down, took her time to read the relevant passages and saw that I was right.

She sat down next to her. 'Mrs Van Bergen, what do you think if I put you to sleep? Do you want that?' Rarely have I heard my mother say 'yes' so eagerly say.

The doctor promised that she would investigate further on Thursday, her day off, and that it would probably happen on Friday afternoon.

After the doctor left, my sister and I explained it again: 'The doctor will put you to sleep and then keep you asleep until you are dead. What do you think of that?' My mother had never had a taste for alcohol all her life, but then she said in a cheerful tone: 'Let's have a drink with that.'

It would be the last time she was funny. Because it became increasingly grim. When she asked me exactly when it was going to happen and I told her to wait until Friday, she tapped her forehead with her index finger and growled, "Bureaucracy."

The day and a half she had to wait was the fourth phase, the most terrible.

At the end of the afternoon on Thursday, the doctor called: it would definitely continue on Friday. In the meantime, she had ordered the medicines from the pharmacy. The pharmacy would deliver it the next day.

The doctor himself would come around noon and explain what was about to happen. Specialized nurses would then insert the IV needle and administer the fluid.

I hung up. I said to P. who had come along to say goodbye: 'It will continue.' There were tears again. They were strange tears. Tears I didn't know. Tears because the time would finally come on Friday.

But it wasn't Friday yet. It was Thursday, early evening. My mother still had a little more than 24 hours to go.

That evening I was alone with her. She was increasingly confused.

Sometimes she hallucinated. 'A banana. I need a banana. There's one here baby. That child needs to eat,' she stammered. No matter what I said, she wanted me to get a banana. "But we don't have any bananas." Would I like to ask the neighbors for a banana? "Okay," I said and walked to the front door. I stood in the doorway and looked at the drizzling January rain. The commotion made the evening even grayer and more dreary than it already was. I wondered how long I had to stand there to be worthy of belief.

Although? Credible? I? What was still believable about the horrific adventure I had plunged her into? After a few minutes I went back inside. "No," I lied, "the neighbors don't have bananas either." Fortunately, the baby seemed to have been forgotten by now.

For a moment she was clear again. 'Give my regards to everyone and wish them all good luck and good health.' She would express that wish repeatedly that evening.

But then it happened again. Now she wanted chocolate. "But you didn't want to eat anymore, did you?" She didn't respond to my words. 'Chocolate, chocolate.' She

it almost begged. I knew there was still chocolate in the fridge so I gave her some. She sucked on a cube for a few seconds, but she lacked the strength to swallow it. She spit it out again and I caught it with a tissue.

When I handed her over to night care, she was asleep. I went upstairs and felt as sickly as the rain swishing in the gutter.

At a quarter to seven the next morning, the night care staff knocked on my bedroom door. Finally I fell asleep and I had intense dreams.

There was a book presentation. I had written a book. Fatal exit.

A kind of chemistry book with complicated formulas in which I explained in detail how you can put together Drion's pill yourself.

"Your mother is asking about you."

She had been haunted all night. She had only slept for one hour, after ten drops of Haldol. "She doesn't put anything on it." The two sleeping pills had also done nothing. We gave her a third pill. Then she slept for a while.

Then things went wrong again. Arms flailing all the time. Constant unrest. "A pill, a pill," she said to the two women from home care who had come to wash her. We thought she was asking for a sleeping pill, but there were none left.

I sat down next to her. 'How long?' she asked, 'when is the doctor coming?'

This was getting too bad. I couldn't keep her waiting any longer. I called the practice and was immediately connected to the doctor.

'You have to give something now. My mother won't make it until this afternoon.'

'Give her haloperidol. Increase the dose to thirty drops.' "So I have to be generous?"

'Better too much than too little.'

I grabbed a teaspoon, but didn't have the patience to count the liquid drop by drop. How many drops would one teaspoon be? I quickly guessed at fifteen.

Or something. I gave her two teaspoons.

Then she was calm. Completely unconscious. It was the end of the fourth phase.

During the morning my sisters arrived. They never saw my mother regain consciousness. The doctor came at a quarter to twelve. I offered her tea, made it, but forgot to pour it.

When she left and hadn't had anything to drink, I said, "I'm normally very different."

The doctor said that our mother would first need a large dose of midazolam

and that after a pump the supply of this sleeping aid would take over. The doctor briefly explained the principle of palliative sedation. We start with the lowest possible dose, because sedation is a so-called proportional action: it is determined with which dose sufficient comfort can be achieved. This could mean that our

mother could wake up because the initial dose was too low. In that case the dose would be increased.

More generally, a patient may become 'tolerant' and the dose of midazolam must be increased for the same effect. If the higher dose no longer has the intended soothing effect, another agent is added. For situations when that combination is no longer effective, a third remedy is kept on hand.

Meanwhile, my mother was sleeping peacefully. "Let's hope for a miracle," we said as we waited for the nurses to arrive.

"Let her die before they come." But she didn't die. As always, things turned out differently than you think. In my mind I had already let her die many deaths in the last five years. Because I had already made everything up once, fate saw no way out. So, all things considered, it was my fault that she was still alive. That's the kind of thing I thought as I waited with my sisters.

The nurses arrived at two o'clock. They connected my mother to the IV. They were two wonderful women. They did their work quietly – with expertise and with a heart for mother and daughters.

But what the doctor warned happened. For my unlucky mother, the initial dose was not high enough. When we wanted to say goodbye to her and to the sister who would be with her until Sunday morning

awake, she blinked and spoke unintelligible words.
Within no time, the nurses we paged returned to increase the dosage.

It was almost dark when we left. When I left, I felt like my mother was no longer alive. In any case, she was no longer aware of anything and that was the most important thing for me.

I was crying terribly at home.

Actually, I don't smoke anymore. But that evening I stole a package.

I felt sad and guilty about the obstacles my mother had to overcome on her way to death. I was also angry. In my mind I sneered that she should have first provided proof of good behavior before she was eligible for palliative sedation. She was right to complain about the bureaucracy. How many man-hours had been spent in recent weeks to ensure that she died within the framework of the law?

It was Saturday morning. For the umpteenth time I let the film of the past few days pass me by in my mind. I was making a cup of cappuccino when it suddenly dawned on me that she hadn't begged for a sleeping pill the morning before. She had wanted 'the pill'!

In fact she had shouted, 'Kill me, kill me.'

With the generous dose of haloperidol I had given her the final blow - at least as far as she was aware. A horrifying, but at the same time beautiful thought.

It was a strange day for my sister who stayed behind. She had a lot of support from the professional staff who came in and out. On a deathbed, 'accidents' are not uncommon. The women from home care cleaned up the mess. They also reassured my sister: the irregular breathing was part of it, just like the fluttering hands. The nurses checked the pump and increased the dosage when she threatened to wake up again. When she started breathing heavily, they placed her on her side.

Then her breathing calmed down. According to them, all signals that the end would come soon.

In the evening my sister went out for some air and that's when it happened. While home care had just changed her, my mother died.

Just after nine my sister called. When we hung up, I said, "Champagne!" P. thought that was inappropriate. The champagne remained untouched. Not because I thought P. was right, but because I was too tired. Too tired and completely worn out.

During the consultation about the inclusion of this text in the guide, Annegreet van Bergen requested that she indicate that she subsequently saw stopping eating and drinking as an emergency step, of which she and her sister have unpleasant memories.

PART 3

Stop offering food and drinking in incapacitated patients with dementia

7. STOP OFFERING FOOD AND DRINKS TO INCOMPETENT PATIENTS WITH DEMENTIA¹⁶

7.1 Summary

- In some situations, incapacitated patients may be diagnosed with dementia, it is discussed whether food and drinks should still be offered.
- This discussion may arise from a written advance directive or a documented oral expression of intent by the patient when he was still competent. This discussion can also be entered into by the representative or by the healthcare providers involved, without there being a written advance directive or documented oral expression of intent from the patient.

¹⁶ The NVVE endorses Chapter 7 of the guide Care for people who are aware not to refrain from eating and drinking. According to the NVVE, it is undesirable to regard the actual behavior of an incompetent person as a valid reason to deviate from a treatment ban drawn up in a competent state. The NVVE fears that interpreting the actual behavior of people with advanced or advanced dementia as a new standard will lead to the erosion of the treatment ban.

Together with the KNMG, the NVVE is of the opinion that healthcare providers cannot be morally required to withhold food and fluid from a person who gives positive signals regarding food and drink, but there is a difference of opinion about the legal basis for this.

- The behavior that the patient with dementia shows with regard to eating and drinking can range from more or less normal eating and drinking (positive verbal and/or non-verbal signals), with or without support from a loved one or healthcare provider, to defensive behavior (defined as: any behavior by a patient that makes or prevents eating or drinking).
- Nursing and care are counted as part of the WGBO medical procedures. This also includes food and drinks. Refusing food and fluid as part of daily care can therefore also be regarded as a refusal to treat. This refusal to treat may be recorded in a written advance directive or expressed verbally.
- A refusal to treat is respected, unless there is a 'justified reason' to deviate from this. The decision about a justified 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 drinks:
 - o patient-related factors:
 - The patient's behavior with regard to eating and drinking is the most important factor for decision making.
 - Observable suffering is not a condition, but it is a factor that can be taken into account when deciding to stop offering food and drinks. Stopping offering food and drinks can therefore also be professionally responsible if there is no observable suffering.
 - The assessment of the representative and/or healthcare providers about the patient's quality of life is a very subjective and questionable criterion, on which consensus cannot often be reached. It is therefore not easy to handle in practice.
 - o the representative's view (also on behalf of the relatives);
 - o the view of the healthcare providers involved;
 - o the presence or absence of a written directive or documented oral expression of intent. The absence of this does not rule out stopping offering food and drinks.

- A decision to stop offering food and drinks in such a situation can only be taken after a careful process. Parts of the decision-making process may include: consulting relevant experts (for example a geriatric specialist, a clinical geriatrician or a geriatric internist) and/or holding a moral consultation.
- The decision to stop offering food and drinks is taken by the responsible healthcare provider, after consultation with the representative and in consultation with the other healthcare providers involved.
- The patient's behavior guides decision-making. The present-
The nature of a written advance directive or documented oral expression of intent plays a limited role.
- If the patient gives positive verbal and/or non-verbal signals regarding food and drinks, food and drinks are not stopped, even if there is a written advance directive or documented oral expression of intent. The discrepancy between the content of the advance directive and the observed behavior is considered a valid reason to deviate from the advance directive. Furthermore, caregivers cannot be expected/required to withhold food and drink from a person who provides positive verbal and non-verbal signals regarding food and drink.
- If it is consistent and not (easily) treatable
defensive behavior with regard to food and drinks and there is a written advance directive or a documented oral expression of intent, then it is professionally responsible to stop offering food and drinks. Permission from the representative is desirable, but not strictly necessary. Even in the case of defensive behavior without a written declaration of intent or documented oral expression of intent, it may be professionally responsible to stop offering food and drinks. In that situation, the decision to stop offering food and drinks can only be taken if there is consensus between the representative and the responsible healthcare provider.
- In the intermediate area (no positive verbal and/or non-verbal signals with regard to food and drinks, and no defensive behavior), stopping offering food and drinks can only be considered in extreme cases, if there is a written declaration of intent. or is a documented oral expression of intent and preferably with the consent of the representative.
- The table below provides a schematic answer to
the question of when it is professionally responsible to stop offering food and drinks to an incapacitated patient with dementia. In every compartment where food and drinks are not ' ' state, is to stop offering professionally responsible. In situations where '++', '+' or '+/-' is stated, stopping offering food and drinks is more or less professionally justified.

Decide to stop offering food and drinks	View of the representative (without written declaration of intent or documented oral expression of intent#)	View of the responsible healthcare provider (without written advance directive or documented oral expression of intent#)	Oral advance directive, documented in medical file#	Written declaration of intent#
Positive verbal and non-verbal cues regarding food and drink
No verbal and non-verbal signals regarding food and drink, but also no defensive behavior	.	.	+/-	+/-
Defensive behavior regarding food and drinks	+* _**	+* _**	++	++

In which the patient indicates that he does not want to be offered food and drinks

++, + Stopping offering food and drinks is to a greater or lesser extent or +/- professionally responsible

. Stopping offering food and drinks is not professionally responsible

* By consensus between the representative and the responsible healthcare provider about stopping the offering of food and drinks

** In the event of a difference of opinion between the representative and the responsible healthcare provider

7.2 Introduction

This chapter discusses the decision-making process regarding stopping offering food and drinks to incapacitated patients with dementia.¹⁷ A discussion about this can arise based on the following situations:

1. The patient has included in a written advance directive that if she has become incapacitated (see also section 2.3), she wants to forego food and fluids. In such an advance directive, the patient can write that she wants to refrain from artificial administration of food and fluid at that moment, but also that she no longer wants to be offered food and drinks from then on. She can see this as an opportunity to maintain as much control as possible over her own life in advance, if she has ended up in a situation that is unacceptable to her.
2. When the patient was still competent, she made verbal statements about stopping offering food and drinks to relatives and/or healthcare providers, which were recorded in the medical file.
3. The representative - in consultation with the relatives - questions the discontinuation of offering food and drinks on the basis of undocumented verbal expressions of intent by the patient or on the basis of the patient's own opinion about what the patient would have wanted and/or what is in the patient's interest at that moment, without a previous written advance directive or documented oral expressions of intent from the patient being present.

¹⁷ There is no question of BSTED in these situations, because a person who has become incapacitated person can no longer consciously stop eating and drinking. If this is done on the basis of a written advance directive, 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 incapacitated after the (conscious) decision to stop eating and drinking are beyond the scope of this chapter.

4. The responsible healthcare provider - in consultation with the other healthcare providers involved - calls into question the discontinuation of offering food and drinks, without a written advance directive or documented oral expressions of intent from the patient being present.

Stopping offering food and drinks can pose legal, ethical and/or practical dilemmas for healthcare providers and loved ones. This chapter first outlines the background of the subject and provides information about the target group of this chapter, patients with dementia, and the consequences of dementia for eating and drinking. Below is a description of the legal context of the decision-making process surrounding the discontinuation of offering food and drinks. Finally, a discussion follows of the factors that play a role in decision-making and its consideration.

The chapter provides a framework within which healthcare providers can consider whether stopping offering food and drinks to an incapacitated patient with dementia is permitted and, if so, under what circumstances. As far as the committee is aware, there are no Dutch or foreign guidelines that discuss stopping offering food and drinks to patients with dementia.

7.3 Background

7.3.1 Target group

People can become incapacitated over the course of their lives, for example due to an illness or an accident. In practice, this often concerns people with dementia. In dementia, it can be anticipated that cognitive functions will decline in the future and that the patient may become incapacitated at some point. That perspective is often not present with many other diseases and accidents, because the incapacity often occurs suddenly and unexpectedly.

This chapter concerns people with dementia who have become incapacitated with regard to the decision to consciously stop eating and drinking.¹⁸ Incompetent means that someone 'is unable

can be expected to make a reasonable assessment of its interests with regard to a decision or situation that is 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 incapacitated. Patients who have been incapacitated all their lives as a result of an intellectual disability fall outside the scope of this chapter. These people have never been able to express or establish their will.

7.3.2 Distinction regarding discontinuation of food and fluid in incapacitated patients with dementia

With regard to stopping food and fluid in incapacitated patients with dementia, a distinction is made between:

1. stopping offering food and drinks if the patient is still able to eat and drink independently;
2. not (anymore) helping with eating and drinking, if the patient requires help from a loved one or care provider;
3. discontinuing or not starting artificial administration of nutrition and/or fluid (by tube, intravenous or subcutaneous).

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

In the Netherlands, long-term tube feeding and parenteral nutrition are used

¹⁸ In the remainder of this chapter, the term 'to the point' will be omitted.

Wherever 'incapacitated' is stated, it is meant 'incapacitated with regard to the decision to stop eating and drinking'.

(as mentioned under 3) only rarely used in patients with dementia. Discontinuation therefore occurs relatively rarely in practice and will not be discussed further here. Not starting artificial administration of food and fluid also falls outside the scope of this guide, as does forcibly administering food and/or fluid (for example in the context of involuntary care).

7.4 Disease course in dementia and the possible consequences for eating and drinking

7.4.1 Disease course in dementia

Dementia generally has a long course (usually in the order of 5-10 years) and is preceded by a period of cognitive deterioration ('mild cognitive impairment') in which dementia is not (yet) present (Quill 2021). The course (both in terms of symptoms and duration) varies per patient and partly depends on the type of dementia. Whether and when incapacity occurs varies greatly and differs per patient and per situation.

7.4.2 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 difficulty swallowing ten);
- no longer being able/knowing how to eat (as a form of apraxia) in the context of cognitive decline; this may involve no longer knowing how to get food to the mouth or no longer knowing how to chew or swallow;
- increasing metabolic dysregulation in the context of anorexia cachexia syndrome, as also occurs in other life-threatening diseases (Guideline Anorexia and weight loss). As a result, patients lose their appetite, gradually eat less and lose weight. Ultimately, the diet will meet its needs

do not cover the body and debilitation, bedriddenness and death occur. Not eating is a consequence of the disease and not the cause of death. Fluid intake remains stable for much longer than food intake.

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

1. A patient with dementia gives positive verbal and/or non-verbal signals send signals regarding food and drink. She then eats, with or without the help of a loved one or care provider.
2. Eating and drinking is accompanied by defensive behavior. With defensive behavior is meant 'any behavior of a patient that makes eating or drinking difficult or prevents' (Groenewoud 2009). Repelling food and drink occurs in many different forms (see table 1).

Table 1. Examples of defensive behavior

Before the meal:

The inhabitant:

- refuses to go to the eating area.

During mealtime:

The resident does not take a bite or a sip:

- verbally refuses (I don't want to);
- does not touch the food;
- pushes away his spoon or plate, or (the hand of) the caregiver;
- bite the spoon;
- turns his head away;
- keeps his mouth closed;
- keeps his teeth together;
- walks away from the table.

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

- cochlear;
- spits out the food or drink;
- removes food from his mouth with his hands;
- does not swallow food or drink.

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

Which signals from the patient are identified as defensive behavior depends on the patient's health and functioning. This will have to be assessed per patient. For example, if someone has swallowing problems due to a stroke, not swallowing solid food cannot be interpreted as defensive behavior.

Defensive behavior can have various causes that can be treated. The [Guideline Dealing with defensive behavior when eating and drinking 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 caregivers in nursing and care homes, but can also be used by doctors and nurses in nursing homes at home or in the hospital. The guideline does not provide advice on stopping offering food and drinks.

In case of defensive behavior, help with eating and drinking by a loved one or care provider will always be necessary, and sometimes also persuasion. Then the question arises as to how far one can and should go with feeding attempts. If caregivers actually try to swallow the food and drink, a gradual transition to involuntary care occurs.¹⁹ Involuntary care is only permitted if there is 'serious disadvantage' and there are no other solutions/alternatives to combat this. That

will have to be assessed on a case-by-case basis in accordance with the legislation (Care and Coercion Act). In practice, involuntary care with regard to nutrition and fluid is only very rarely applied to patients with dementia.

3. There is an intermediate area between 'normal eating' and immune behavior, in which the patient does not give positive signals regarding food and drink, but also does not show any defensive behavior. In this case, help from a loved one or caregiver with eating and drinking will always be necessary, because the patient will not eat or drink on her own if this is presented to her.

Behavior regarding food and drink is an important factor in decision-making (see section 7.6 and section 7.7).

7.5 Legal context

Offering food and drinks is a daily part of nursing and caring for patients. Food and drink are necessary to maintain the patient's life. Refraining from offering food and fluid without justification in a care-dependent situation is not acceptable and would also constitute a criminal offense.²⁰

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

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

²⁰ Article 255 of the Criminal Code

7.5.1 The refusal of treatment

A competent person can 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 (the so-called refusal of treatment).²¹ This concerns, for example, resuscitation or other life-prolonging treatment. Nursing and care are considered medical procedures according to the WGBO (Article 7:466 paragraph 3 of the Dutch Civil Code). This also includes food and drinks. Refusing food and fluid as part of daily care can therefore also be regarded as a refusal to treat. This refusal to treat may be recorded in a written advance directive or expressed verbally. These statements only apply as soon as someone can no longer determine her will. If the patient is still able to do so, the current expression of intent applies.

According to the WGBO, the care provider must respect a written advance directive containing a refusal to treat, unless there are justified reasons to deviate from this,²² for example in the event of uncertainty about the authenticity, signature or content of the advance directive. The legislative history does not provide an exhaustive list of what should be understood by well-founded reasons. The following is said about this in the Memorandum on the legal status of advance directives in healthcare: 'It is (...) not really possible to give a concrete, generally applicable answer to the question of what 'well-founded reasons' can be for deviation from the advance directive. Practice, and where appropriate the judgment of the (disciplinary) judge, will have to show what 'well-founded reasons' can be for deviating from a written directive'.²³ The WGBO leaves the judgment to the care provider (Leenen 2020).

An oral expression of intent addressed to a healthcare provider, which is documented in the medical file, in principle has the same value as a written declaration of intent. After all, what matters is that the patient has clearly stated that he or she does not consent to treatment in certain situations. A written advance directive generally offers more clarity. Therefore, patients are advised to wish

such as putting a refusal of treatment in writing with a clear statement of the situations in which the refusal of treatment applies, to discuss this with the healthcare provider and to regularly reconfirm or update the statement, in any case if the patient's opinion whether the situation has changed. This chapter assumes that the advance directive is current at the time when stopping offering food and drinks is considered.

7.5.2 Representation

If a patient is no longer able to give consent for treatment or other care ('incompetent'), she will be represented by another person. The representative acts 'in the spirit of' and in the interests of the patient. See further section 4.9.

7.6 Considerations when stopping offering food and fluid to patients with dementia

This section discusses factors that play a role in the decision-making process about stopping offering food and drinks to incapacitated patients with dementia. It's about:

- patient-related factors;
- the representative's view;
- the view of healthcare providers;
- the presence or absence of a written directive or previous documented oral expressions of intent.

²¹ Refusal of treatment involves a negative advance directive. In this letter, the patient describes what care or treatment she no longer wishes to receive in a particular situation. In a positive advance directive, a patient requests the doctor to perform certain actions or to initiate or continue treatment. See Will declaration | KNMG.

²² Article 7:450 member 3 BW.

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

Section 7.7 discusses the consideration of these factors in decision-making.

7.6.1 Patient-related factors

Patient behavior towards eating and drinking

In the process of dementia there can be major differences with regard to food and drink. These range from actively eating and drinking to consistently displaying defensive behavior (see section 7.4.2). In between, there may be a reduced interest in food and drink. The nature and consistency of behavior with regard to eating and drinking are the most important factors in deciding whether to stop offering food and fluid.

If there is defensive behavior, diagnosis of treatable causes is recommended. Treatment of the causes of defensive behavior is indicated if it concerns a simple, non-invasive and potentially effective treatment (e.g. pureeing food or treatment of candidal stomatitis). Assessing the consistency of the defensive behavior and the effect of any treatment thereof will generally take a number of weeks.

Perceptible suffering of the patient and/or a quality of life assessed as poor by relatives and healthcare providers

The question is whether observable suffering of the patient and/or a quality of life assessed as poor by relatives and care providers should play a role in decision-making.

The patient's behavior (for example crying or shouting) may indicate that he or she is suffering seriously. Perceptible suffering can be both psychological and physical, and can be the result of dementia or another associated 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 drinks.

Stop offering

Eating and drinking can therefore also be professionally justified if there is no observable suffering. Defensive behavior 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 healthcare providers. This may lead to a discussion about stopping offering food and drinks. However, quality of life is a sub-

jective and questionable criterion, on which no consensus can often be reached and which is not easy to handle in practice. It is therefore not taken into account in decision-making.

7.6.2 Representative's View

The representative's views play an important role in the decision whether or not to stop offering food and drinks. 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 in the interests of the now incapacitated person, taking the current situation as leading. She takes the opinions of (other) loved ones into account in her opinion.

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 he was still competent. She may also have been involved in drawing up an advance directive and/or discussions with the doctor about this subject. If the subject has never been discussed, the representative may have his or her own thoughts about what the patient would have wanted in the situation she is currently in. The representative serves solely the interests of the patient and makes 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 behavior and current wishes, interests and preferences and in interpreting a written or documented oral advance directive.

7.6.3 Views of healthcare providers

The views of the healthcare providers involved also play an important role in the decision whether or not to stop offering food and drinks. There is often a long-lasting and intensive one involvement of healthcare providers (particularly caregivers) with the patient, so that they can properly interpret the patient's expressions. They may also have strong opinions about stopping offering food and drinks.

7.6.4 Presence or absence of a written directive or documented oral expressions of intent

The question is whether and to what extent the previous written or documented oral expressions of intent of the then still competent person are still leading for the current situation of an incapacitated person with dementia. The previous expressions of will may conflict with the current wishes, interests and preferences of the patient with dementia. For example, people with dementia can write down in an advance directive that they no longer want to be offered food and drink in a situation of incapacity, while once in that situation they will still consume 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 you have (advanced) dementia does not add or detract from this. The current wishes, interests and preferences of a patient with dementia therefore deserve to be respected. This is also stated in the UN Convention on Disabilities, which also applies to (incapacitated) people with

dementia.²⁴ This also applies in the event that the patient has indicated in an advance directive in the past that she does not wish to receive food and drink if she has become incapacitated in this regard. Because the need of the incapacitated 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 mainly based on observations and interpretations of the patient's behavior. .

The presence of a written advance directive or a documented oral expression of intent from the patient therefore plays a limited role in decision-making.

If there is no written or documented oral declaration of intent, the offering of food and drinks may be questioned by the representative or by the healthcare provider(s) involved. In that case, the patient's behavior is leading (see below). It is advisable to consult one or more (not involved) colleagues in advance when making decisions.

7.7 Decision-making

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

²⁴ According to Article 12(4) of the UN Convention on Disabilities, the starting point is that the current wishes and expressions of the incapacitated client are taken into account.

²⁵ Stopping offering food and drinks to patients with dementia and the role of an advance directive are discussed in various English 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).

In this situation, a balance must be found between the patient's previous views and the current wishes and preferences of the patient with dementia (De Kort 2017). Parts of the decision-making process may include: consulting relevant experts, for example a geriatric specialist, a clinical geriatrician or a geriatric internist, and/or holding a moral consultation.

The decision partly depends on the actual situation that arises. Current behavior with regard to food and drink (see section 7.4.2) is leading. The presence of a written advance directive or a documented oral expression of intent plays a limited role.

The responsible healthcare provider makes the decision to stop offering food and drinks after consultation with the representative and the other healthcare providers involved. In the home situation, the responsible care provider will almost always be the general practitioner, in the nursing home the geriatric specialist and in the hospital the medical specialist.

7.7.1 Decision making in the presence of positive verbal and/or non-verbal signals regarding food and drink

It is not professionally responsible to stop offering food and drinks if the incapacitated patient gives positive verbal and/or non-verbal signals with regard to food and drinks. This is independent of the existence of a written directive or a documented oral expression of intention, and of the view of the representative.

If the patient has indicated in a previous advance directive or in a documented oral expression of intent that she no longer wishes to be offered food and drink in the event of dementia, this declaration will not be followed in this situation. The reason for this is that there is a discrepancy between the patient's current behavior

and the previously drawn up advance directive. This discrepancy is a reason to continue offering food and drinks. The committee sees this as an interpretation of the legal requirement of 'well-founded reasons' to deviate from a previously drawn up advance directive (see section 7.5.1).

In addition, from the perspective of the healthcare providers involved, they cannot be expected/required on moral grounds to withhold food and drink from a person who gives positive verbal and non-verbal signals with regard to food and drink.

7.7.2 Decision-making in defensive behavior

This section assumes a situation in which there is defensive behavior, but with great difficulty it is still possible to get food and drink into the patient's mouth. If this is no longer possible, force-feeding should be considered. In most cases this will not be applied. The decision-making process in this regard falls outside the scope of this guide.

If the patient consistently shows defensive behavior for which treatment is not possible or ineffective, and if there is a written or documented oral advance directive, no food and drinks are offered. In this situation there is no discrepancy between the patient's behavior and the content of the advance directive or documented oral expression of intent. Permission from the representative to stop offering food and drinks in this situation is desirable, but not strictly necessary.

Even without a written or documented oral declaration of intent, stopping offering food and drinks can be professionally responsible if someone consistently shows defensive behavior.

Consensus between the representative and the responsible healthcare provider is a requirement.

It is conceivable that the defensive behavior will disappear if food and drink are no longer offered and that the patient will then send positive signals with regard to food and drink. In that case, the decision not to offer food and drinks will be reconsidered.

7.7.3 Decision-making in the absence of positive verbal and/or non-verbal signals with regard to eating and drinking as well as defensive behavior

In the situation where the patient does not give positive verbal or non-verbal signals regarding food and drink, but also does not show any defensive behavior, she is completely dependent on the care provider to eat and drink. In this situation, in extreme cases, a decision can be made to stop offering food and drinks, provided there is a written advance directive or a documented oral expression of intent. The content of the advance directive or the documented oral expression of intent plays a role in particular. What situation is being described and intended, and is that specific situation currently in question? The responsible healthcare provider makes the decision to stop offering food and drinks in consultation with the other healthcare providers involved and with the representative. This decision will always have to be supported by a multidisciplinary team based on patient-related considerations. If there is any doubt, food and drinks are not stopped.

Here too, the decision to no longer offer food and drinks can be reconsidered if the patient starts to give positive signals regarding food and drinks.

If there is no written advance directive or documented oral expression of intent and no defensive behavior, stopping offering food and drinks in this situation is not professionally justified.

7.7.4 Decision-making and emotional burden on relatives and healthcare providers

Stopping offering food and drinks can be emotionally stressful for both loved ones and caregivers. Offering food and drinks is seen as a basic form of care. Both parties have often been involved in the care of the patient with dementia for a long time. They may have strong feelings and opinions regarding the perspective of (not) offering food and drinks. This requires good guidance and support from relatives and healthcare providers, both during the decision-making process and when implementing the decision to stop offering food and drinks.

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 drinks. In the latter situation, they can invoke conscientious objections (see section 4.11), provided they transfer the care to others.

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ATTACHMENT 1

Commission

- Dr. E. Bolt, general practitioner, researcher, on behalf of NHG
- EG Burgering, MSc, general policy advisor KNMG
- Mr. C. Compier, NVVE policy officer
- Dr. R. van Deijck, specialist in geriatric medicine, palliative care physician, on behalf of Verenso

- Mr. Dr. V. Derckx, KNMG health law advisor
- E. Dierink, nursing specialist, on behalf of V&VN
- G. van Dijk, MA, KNMG ethics policy advisor • Dr. A. de Graeff, internist-oncologist, hospice doctor, on behalf of NIV, chairman of the committee
- Drs. D. van Maare, general practitioner, palliative care specialist, on behalf of NHG
- Drs. P. van Mierlo, clinical geriatrician, palliative care physician, on behalf of NVKG
- H. Speerstra, coordinator of the NVVE advice center (until June 2022)
- N. Schrijver, nursing specialist, on behalf of V&VN (from December 2022)
- SEM Sommers, MSc, physician assistant, named NAPA (dead September 2022)
- K. Tol, nursing specialist, on behalf of V&VN (until December 2022)
- Mr. L. De Vito, lawyer NVVE (from June 2022)
- H. van der Weerd, community nurse, on behalf of V&VN

Sounding board group

- Dr. S. Bekkers, cardiologist, on behalf of NVVC
- L. Bisschops, chairman of KBO Brabant, on behalf of KBO Brabant
- G. Deleij, policy advisor for advocacy, on behalf of KBO-PCOB (from May 2023)
- J. Gootjes, general manager, director, on behalf of the Hospice Care Association The Netherlands
- M. van Oort, head of advocacy, on behalf of KBO-PCOB (until May 2023)
- W. Toersen, senior patient interest advisor, on behalf of the Patient Federation The Netherlands
- J. van der Velden, general practitioner, advisor, trainer on behalf of Pharos
- Prof. Dr. K. Vissers, anesthesiologist – Pain specialist & consultant Palliative care, professor of Pain and Palliative Medicine, in a personal capacity
- E. Willemsen, policy officer, on behalf of KBO-Brabant

APPENDIX 2

1. Introduction

In order to obtain the most complete overview possible of recent literature on consciously refraining from eating and drinking to hasten the end of life, it was decided to conduct a systematic literature review over the period 2010-2021. All types of articles were included: empirical research, case studies, (systematic) reviews and reflective articles. This chapter discusses the search strategy and the search results.

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

2. Search strategy

Search date: January 7 & 10, 2022

Databases: OVID Medline, PubMed, Embase, Cochrane Library

Search limits:

- Publication date: 2010-2022

- English Dutch; - Study

type: no limit.

Search syntax:

MEDLINE (OVID) – January 7, 2022

- ¹ Euthanasia, Active, Voluntary/ (1798)
- ² Euthanasia, Passive/ (5984)
- ³ Personal Autonomy/ (17902)
- ⁴ Right to Die/ (4950)
- ⁵ Suicide, Assisted/ (5995)
- ⁶ Treatment Refusal/ (12057)
- ⁷ Withholding Treatment/ (12517)
- ⁸ Advance Directives/ (6360)
- ⁹ 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 volunteer*.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) - January 7, 2022

- ¹ Euthanasia, Active, Voluntary/ (3)
- ² Euthanasia, Passive/ (0)
- ³ Personal Autonomy/ (6)
- ⁴ Right to Die/ (0)
- ⁵ Suicide, Assisted/ (8)
- ⁶ Treatment Refusal/ (0)
- ⁷ Withholding Treatment/ (12)
- ⁸ Advance Directives/ (8)
- ⁹ or/1-8 (34)
- 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 volunteer*.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) – January 10, 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'/de	20727
#7 'treatment withdrawal'/de	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'/de	135756
#14 'dehydration'/exp	46720
#15 'fasting'/de	15207
#16 'starvation'/exp	22168
#17 'food deprivation'/de	7394
#18 'feeding behavior'/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 volunteer*.ti,ab	98974
#22 refuse*.ti,ab OR withhold*.ti,ab OR stopping.ti,ab OR cessat*:- of, 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 [pubmed-not-med-line]/lim)	887

COCHRANE LIBRARY (via wiley) – 10 januari 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 #9 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8	121 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 #18 #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17	3451 15350
#19 #9 and #18	20
#20 volunteer*:you #21	13267
refuse*:you #22	5383
withhold*:you #23 stopping*:you	892
#24 cease*:you #25	5725
eating:you #26 drinking:	16291
ti,ab #27 food*:ti,ab #28	13204
fluid*:ti,ab	9664
	43323
	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 #33	1
#19 or #31 or #32 with Cochrane Library publication date Between Jan 2010 and Jan 2022	47

PUBMED – January 10, 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 behavior"[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 "drinking" [Title/Abstract] OR "food*" [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 lists the general search results.

Table 3.1. General 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 STED.

The full text of the remaining 167 references was searched. Based on the full-text evaluation, an additional 79 references were excluded.

3.1 Included references

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. <i>New England Journal of Medicine</i> , 2018. 378(1): p. 73-79.	Not about VSED
Clinicians and the right to decide on withdrawal of treatment. <i>Bmj</i> , 2017. 356: p. j15.	Is about stopping nutrition and fluid in vegetative state
Ackermann, R.J., Care of Patients at the End of Life: Advance Care Planning. <i>Fp Essentials</i> , 2016. 447: p. 25-31.	General story about ACP in dementia; only stopping artificial administration of food and fluid is discussed
Barilan, Y.M., The Role of Doctors in Hunger Strikes. <i>Kennedy Institute of Ethics Journal</i> , 2017. 27(3): p. 341-369.	It's about prisoners' hunger strike
Beldon, P., Conflict in care: Respecting the decision of the individual. <i>Wounds UK</i> , 2014. 10(1): p. 48-50.	It's about discontinuing 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. <i>BMC Palliative Care</i> , 2017. 16(1): p. 7.	Is about refusing artificial administration of food and fluid
Brar, K., H.M. Mekala, and S. Lippmann, Dehydration in terminal illness: Which path forward? <i>Journal of Family Practice</i> , 2018. 67(10): p. E1-E3.	Is about correction of dehydration in the dying phase
Buck, H.G., Refusing artificial nutrition and hydration in advanced illness. <i>Nursing</i> , 2012. 42(9): p. 12-3.	Is about refusing artificial administration of food and fluid
Bui, G.T., et al., Prevalence and contents of advance directives in patients receiving home parenteral nutrition. <i>Journal of Parenteral and Enteral Nutrition</i> , 2016. 40(3): p. 399-404.	Is about patients who receive parenteral nutrition
Carlin, E., R. Dubash, and J. Kozlovski, End of life care in the emergency department. <i>EMA – Emergency Medicine Australasia</i> , 2020. 32(3): p. 504-506.	Gaats over 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. <i>Journal of Medical Ethics</i> , 2014. 40(7): p. 501-4.	Is about refraining from artificial administration of food and fluid
Cheon, E., et al., Session 5: End of life feeding. <i>Physiology and Behavior</i> , 2020. 224.	It's about nutrition in the terminal phase

Chuang, I.F., et al., Consistency in end-of-life care preferences between hospitalized elderly patients and their primary family caregivers. <i>Patient Preference and Adherence</i> , 2020. 14: p. 2377-2387.	Not specific about it PLACE
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. <i>Journal of Critical Care</i> , 2018. 48: p. 178-182.	Not specific about it PLACE
Colby, W.H., Nancy Cruzan and the Withhold Versus Withdraw Dilemma. <i>Am J Bioeth</i> , 2019. 19(3): p. 1-2.	About stopping tube feeding in dementia
Constable, C., Withdrawal of artificial nutrition and hydration for patients in a permanent vegetative state: changing tack. <i>Bioethics</i> , 2012. 26(3): p. 157-63.	Is about stopping nutrition and fluid 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?]. <i>Revue Neurologique</i> , 2015. 171(2): p. 115-7.	Is about stopping nutrition and fluids after stroke
Damghi, N., et al., Withholding and withdrawing life-sustaining therapy in a Moroccan Emergency Department: An observational study. <i>BMC Emergency Medicine</i> , 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. <i>Journal of Medicine</i> , 2010. 66(9): p. 436-440.	Is about refraining from artificial administration of food and fluid at the end of life
Druml, C., et al., ESPEN guideline on ethical aspects of artificial nutrition and hydration. <i>Clinical Nutrition</i> , 2016. 35(3): p. 545-56.	Is about ethical aspects of artificial administration of food and fluid
du Toit, J. and F. Miller, The Ethics of Continued Life-Sustaining Treatment for those Diagnosed as Brain-dead. <i>Bioethics</i> , 2016. 30(3): p. 151-8.	Is about life-sustaining treatment for brain death
Dyer, C., Leading campaigner for legalising assisted suicide dies from starvation. <i>BMJ</i> , 2014. 349: p. g7872.	Description of legal affairs at STED at MS
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Colophon

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The 'Care guideline for people who stop eating and drinking to hasten the end of life' has been endorsed by the medical federation KNMG, the professional associations NAPA, NHG, NIV, NVKG, Verenso, V&VN and the NVVE association.

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