

Caring for people who consciously choose not to eat and drink so as to hasten the end of life



Colophon

Caring for people who consciously choose not to eat and drink so as to hasten the end of life is a guide the Royal Dutch Medical Association (KNMG) and the Dutch Nurses' Association (V&VN), 2014.

www.knmg.nl/publicatie/afzien-eten-drinken
www.knmg.nl/english

Contact details KNMG PO Box 20051 3502 LB Utrecht – 0031 (30) 282 38 00 - www.knmg.nl/english

Texts from this publication may be reproduced, provided the source is acknowledged in full.

Contents

/	Summary	4
1	/ Introduction	7
2	/ Characteristics and definitions	10
3	/ Empirical data	13
4	/ Legal and ethical aspects	19
5	/ Care and guidance by professionals, volunteers and those close to the patient	25
6	/ Dealing with defensive behaviour	41
/	Appendices	
	Appendix I KNMG's position on euthanasia and professional responsibility	45
	Appendix II Committee composition	46
	Appendix III Experts consulted	47
	Appendix IV References	48

Summary

In 2011 the Royal Dutch Medical Association (KNMG) ascertained in its position paper entitled *The role of the physician in the voluntary termination of life* that physicians must be better trained to provide guidance to patients who consciously choose not to eat and drink so as to hasten the end of life. It is expected that care providers will increasingly face this situation. This guide issued by the KNMG and the V&VN Dutch Nurses' Association will help physicians, nurses and carers in preparing these patients for and guiding them through the process, and in initiating or continuing palliative care.

This guide does not address the issue of *whether* to stop eating and drinking is the appropriate pathway. Consciously choosing not to eat and drink to hasten the end of life is a choice each and everyone can and may make for themselves. Consciously choosing not to eat and drink is comparable to refusing a treatment which will result in death. This is not regarded as suicide but rather as the patient exercising their right of self-determination, particularly the right to refuse care. By extension, all physicians have a duty to enter into dialogue with a patient about choosing not to eat and drink should the patient raise the matter. Physicians likewise may raise the matter themselves if they have indications that the patient is considering stopping eating and drinking, or may already have done so.

It is imperative to provide proper medical and nursing care to a patient who has consciously chosen not to eat and drink. If a care provider has conscientious objections to providing such care, patient care may be assigned to a colleague care provider. However, a patient should not be deprived of the care required when consciously choosing not to eat and drink. A care provider who invokes conscientious objections should, as befits a good care provider, provide care until such time as a colleague takes over this duty.

The care provider's actions are directed towards adequately and proportionately relieving the patient's suffering. The care provider provides the patient information, prepares the patient for the process and guides him through it. The care provider explores the patient's request for assistance and informs the patient as thoroughly and objectively as possible about the expected course, and the advantages and disadvantages.

This guide emphatically advises patients under 60 years of age who are not suffering from a life-threatening illness against choosing not to eat and drink to hasten the end of life. Older patients need not be advised against consciously choosing not to eat and drink, even if they are not suffering from a life-threatening illness or are still in a good state of health. The patient's decision to stop eating and drinking quite often relates to a request for euthanasia that has been turned down. The considerations underlying the refusal of the request for euthanasia should be discussed during the conversation. It is important to inform the patient that consciously choosing not to eat and drink to hasten the end of life requires perseverance. It requires a constant effort on the part of the patient, with which he confirms his wish to die.

This guide underlines the importance of the continuity of care. During the provision of intensive care to a patient, good collaboration and frequent communication is vital not only among the care providers but also with the patient and especially with those close to the patient (particularly if the latter have difficulty in coming to terms with the patient's decision). Those close to the patient play a crucial role in the provision of care and guidance, and as an intermediary between the patient and the physician. They must receive proper guidance. Caring for a patient who has consciously chosen not to eat and drink may also be stressful for care providers and volunteers. During the process attention must equally be paid to the emotions of all care providers involved (including any volunteers).

The guide describes the preparatory and implementation phases (broken down into the first, middle and dying phase), and the care that should specifically be provided during these phases.

The preparatory phase involves the following:

- ▶ providing information, preparing and supporting the patient and those close to the patient;
- ▶ adapting the medication: stopping unnecessary medication, finding alternative routes of administration and providing medication for sleeping problems, pain and other expected symptoms;
- ▶ providing the required facilities, such as a high-low bed, an anti-decubitus mattress, a lavatory chair, a bedpan or urinal and mouth care products.
- ▶ organising and coordinating care;
- ▶ drawing up a written living will and appointing a legal representative.

In the early stages of the implementation phase the patient more or less gradually stops eating and drinking, usually over the course of a few days but may sometimes do so faster or more slowly. A start should be made with the general personal care of the patient (depending on the patient's physical condition) as well as with mouth care. Where possible, those close to the patient should be involved in providing mouth care since they will usually be at the patient's bedside most of the time. The care provider (usually the nurse, and occasionally the physician) should thoroughly examine the patient's mouth at least once a day to enable the early detection of mouth problems.

Once the patient has stopped eating and no longer or hardly drinks at all, he will grow weaker and become bedridden. The duration of this middle phase varies. Depending in part on the severity of any illness the patient may be suffering from, this phase (with a minimum fluid intake) will last no longer than one to two weeks. If the patient has not minimised the amount of fluid he drinks (< 50 ml/24 hours), it may take a few more days and weeks before the patient dies. It is vital to provide adequate non-pharmacological and pharmacological treatment for complaints and problems occurring during this period (pain, urination complaints, constipation, sleeping problems, restlessness and confusion).

A patient who has stopped eating and drinking may become delirious and (unconsciously) ask for something to drink. This may create a difficult situation, in which the parties concerned can fall back on the relevant agreements made during the preparatory phase and/or in a living will. It is crucial for care providers, particularly if a difficult situation arises, not to suddenly interfere with the agreements previously made with patients and offer them something to drink. If patients are offered fluid, they will fail to reach their desired goal. For this reason it is essential to prevent and treat delirium using the non-pharmacological measures described in this guide, in addition to pursuing an anticipatory policy, combined 'where necessary' with medication policy in the event the patient becomes restless or delirious.

In some cases palliative sedation may be initiated. The complaints and symptoms often are exhaustion and/or delirium, but sometimes permanent thirst may also occur. This is referred to as a refractory situation in that the patient has not granted consent to offer or artificially administer fluid (the symptom therefore is untreatable) and the intake of fluid would lead to prolonging the patient's life against their express wishes. If the patient is also experiencing unbearable suffering, this means that there is an indication for palliative sedation. The patient's consent for initiating palliative sedation is not required. Palliative sedation does not hasten the dying process, provided that it is applied in accordance with the guideline.

The dying phase essentially proceeds no differently to that of patients suffering from a life-threatening illness. Death is regarded as a natural death. Choosing not to eat and drink is recorded as the immediate cause of death on the death certificate.

This guide was developed by the KNMG in association with the following parties:

- ▶ V&VN Dutch Nurses' Association
- ▶ The Dutch College of General Practitioners (NHG)
- ▶ Verenso, the Dutch Association of Elderly Care Physicians and Social Geriatricians
- ▶ Netherlands Society of Clinical Geriatrics (NVKG)
- ▶ The Medical Advisory Committee of the Dutch Association for Voluntary Euthanasia (NVVE)
- ▶ Protestant-Christian Senior Citizens' Association (PCOB)
- ▶ Union of Catholic Senior Citizens' Associations (KBO)

Of the participating professional and scientific associations, the NHG and Verenso have approved the contents of this guide, which the NVKG and V&VN Dutch Nurses' Association have authorised.

1 / Introduction

Background

The KNMG's position paper entitled *The role of the physician in the voluntary termination of life* (KNMG 2011-I) examines the role, responsibilities and limitations of physicians in matters surrounding the voluntary termination of life. The position paper examines factors such as the tension between the citizen's emphatically claimed right of self-determination in the individual's right to end his life and the role that the physician fulfils by providing the requested assistance

In some cases a patient consciously chooses not to eat and drink because the due care criteria for euthanasia have not been fulfilled. A patient with a strong wish to die is occasionally refused euthanasia by his physician. In such cases the physician has a moral and professional duty to help patients find in a timely manner a physician who has no emotional or fundamental objections to euthanasia and assisted suicide. The KNMG's position on this topic is set out in Appendix I. Furthermore patients, as well as physicians, may have fundamental or emotional objections to euthanasia or assisted suicide. Some patients do not wish to trouble their physician with a request for euthanasia while others believe that implementing voluntary termination of life is the individual's own responsibility. Consequently, physicians are not always informed of, or involved in cases where a patient chooses not to eat and drink for the purpose of hastening the end of life.

In the position paper referred to above the KNMG underlines that every physician should enter into a serious dialogue with patients who have expressed a wish to die, also if it stems, for instance, from a sense of having completed life. After all, physicians have a duty to provide their patients with all the information they need to make a carefully considered choice. If a patient raises the matter of choosing not to eat and drink, the physician has a duty to discuss it. The physician should listen carefully to the patient's fears, concerns and motives. The individual concerned is someone who consciously makes a decision to embark on an ultimately irreversible process. This requires that physicians, nurses and carers should respect that choice and demonstrate compassion with the patient (not only as a care provider but also as a fellow human being). Physicians likewise may raise the matter themselves if they have indications that the patient is considering stopping eating and drinking, or may already have done so.

Although physicians have more experience than expected in dealing with patients who had chosen not to eat and drink to hasten the end of life, they are, as became apparent during the KNMG debate evenings, insufficiently trained to prepare and offer guidance to such patients. Physicians therefore have a great need for guidance in this area. Against this background the KNMG established a committee, in which it works closely with V&VN Dutch Nurses' Association.

The KNMG anticipates that this guide will meet a need among physicians, nurses and carers in that more so than in the past they may need to deal with patients who consciously choose not to eat and drink to hasten the end of life. This primarily relates to older patients who, partly on account of the public debate (possibly reinforced by the *Uit Vrije Wil* ('Free Will') citizen's initiative concerning the voluntary termination of life), will more often ask their general practitioner (GP) questions about a completed life, suffering from life and consciously choosing not to eat and drink.

Composition, remit and guiding principles

In 2012 the KNMG established a committee, for which it selected members from the broadest possible range of professional backgrounds and areas of expertise (see Appendix 2). The Committee's remit is as follows:

'The KNMG has ascertained that physicians are insufficiently trained to provide guidance to patients who consciously choose not to eat and drink to hasten the end of life. The Committee has been given the remit to draw up a guide to enable physicians, nurses and carers to properly prepare patients for the process, guide them through it and to initiate or continue adequate palliative care if patients have made that choice.'

The committee adheres to a number of guiding principles. In principle, this guide concerns adults with capacity to decide who wish to hasten the end of their life. This guide does not address the issue of *whether* to stop eating and drinking is the appropriate pathway. Consciously choosing not to eat and drink is a pathway people may choose if they wish to die. Hastening the end of life by consciously choosing not to eat and drink is a drastic choice for patients and those around them. Care providers have a duty to explore the concerns, fears and distress underlying the intended decision. It is conceivable that the individual may make another choice during the exploratory process. This guide deals with the manner in which people should receive guidance from physicians, nurses and carers once they have made that choice. Societal and social issues surrounding this theme fall outside the scope of this guide.

Committee working method and accountability

The committee held ten meetings between 26 April 2012 and 2 October 2013. Based on a work plan drawn up by the committee, a study of national and international literature was conducted and draft texts were prepared, for which the relevant guidelines and protocols were also consulted. The Committee subsequently reviewed, amended where necessary and approved the draft texts. Comments from experts were also incorporated (see Appendix 3). The draft version was subsequently posted on the website of the Dutch Royal Medical Association (KNMG), the Dutch College of General Practitioners (NHG), Verenso (the Dutch Association of Elderly Care Physicians and Social Geriatricians), the Netherlands Society of Clinical Geriatrics (NVKG) and V&VN Dutch Nurses' Association. Furthermore the KNMG organised four debates in KNMG districts.¹ The NHG and Verenso have approved the contents of this guide, which the NVKG and V&VN Dutch Nurses' Association have authorised. The Federation Board of the KNMG approved the guide on 16 October 2014.

Target group and purpose of the guide

This guide is primarily intended for physicians, nurses and carers. It will enable them to properly prepare patients for the process, guide them through it and to initiate or continue palliative care. It may also be read and used by patients and those close to the patient. The guide is not intended as guidance for hunger or thirst-strikers or to assist patients suffering from anorexia nervosa. There are other options for voluntarily terminating life in a humane manner but they have not been specified in this guide.

¹ Rotterdam, The Hague; Amsterdam, Spaarne Amstel, Gooi Eemland and North West Veluwe, Flevoland Zwolle; Groot Gelre, Stedendriehoek and Friesland.

Reader's guide

Chapter 2 describes the relevant characteristics and terms. Chapter 3 explains the empirical data. Chapter 4 sets out the legal and ethical aspects. Chapter 5 offers guidance to professionals, volunteers and those close to the patient about caring for and offering guidance to a patient who has consciously chosen not to eat and drink. Chapter 6 describes how those around the patient should deal with patients who show defensive behaviour.

2 / Characteristics and definitions

2.1 People and patients

On the one hand, this guide relates to people who are not suffering from an illness and, on the other hand, to patients whose condition is deemed to be an illness or a combination of illnesses and complaints by a physician. In the latter case a medical basis exists (KNMG 2011).² People who are not ill, but who consult a physician, nurse or carer at any time concerning their intention to consciously choose not to eat and drink so as to hasten the end of their lives, become a ‘patient’ in the context of the physician-patient relationship, as defined in the Medical Treatment Contracts Act (*Wet op de geneeskundige behandelingsovereenkomst*).³ The term ‘patient’ is used hereinafter in this guide.

2.2 Consciously choosing not to eat and drink to hasten the end of life

The phrase ‘consciously choosing not to eat and drink to hasten the end of life’ implies an individual’s own decision to no longer eat and drink, the purpose of which is to hasten the end of life. This also means declining any food and drink offered and declining the artificial administration of food and fluids.

English literature uses terms such as ‘voluntarily stopping eating and drinking’ (Quill 1997, 2000 and 2012, Jansen 2004, Schwartz 2007, Ivanic 2014), ‘the voluntary refusal of food and fluids’ (Quill 2000-II, Ganzini 2003, Harvath 2004, Rady 2011) and ‘voluntary dehydration’ (Jacobs 2003).⁴ These terms are strongly associated with the literature, culture and case law in the United States of America.

The committee has chosen to incorporate the words ‘consciously choose not to’ in the description used because they express that this involves a conscious choice the individual makes for himself. The committee has therefore not included terms, such as ‘voluntary’, ‘refuse’ and ‘deny’. Nor does it use the phrase ‘stopping stop eating and drinking’ (*versterven* in the Dutch version) in view of the fact that very different meanings can be ascribed to it. ‘Consciously choosing not to eat and drink’ is essentially different to gradually taking in less food and drink as part of a terminal illness process or as a consequence of old age in that the latter is not an active choice made by the patient.

For readability, the addition of ‘to hasten the end of life’ has been omitted as far as possible.

2.3 Artificially administering food and fluids

The decision to begin or stop artificially administering food and fluids is deemed a medical decision. Nurses and carers can play a role when food and fluids are administered through a feeding tube or drip, provided they are authorised and qualified to do so under the Individual Healthcare Professions Act (*Wet op de beroepen in de individuele gezondheidszorg*, BIG). This equally applies to a nurse who inserts and removes the feeding tube or drip.

² Patients may develop complaints that cannot be traced to a specific (classifiable) disease,

³ See Section 7: 446(1) of the Dutch Civil Code (Burgelijk Wetboek), part of the Medical Treatment Contracts Act.

⁴ The terms listed above are not exhaustive.

2.4 Deciding against treatment

Under the Medical Treatment Contracts Act, a patient has the right to receive clear information from the physician about his medical condition, the prognosis and treatment options. Based on the information provided, the patient can either choose to grant or not grant care providers consent to provide treatment, nursing or care.⁵ A patient always has the right to decide against treatment, nursing and care, or against specific aspects thereof. Should the patient not grant consent, the care providers may not provide treatment, nursing or care.

2.5 Capacity/ lack of capacity to decide

A patient must be deemed to have capacity to make their own decisions regarding the medical care they receive until determined otherwise (KNMG 2004). Capacity to decide may fluctuate over time and may vary depending on the area of the decision or action concerned. The following aspects are typical of a patient who has capacity to decide on a matter:

- 1 the ability to express a choice;
- 2 the ability to understand the relevant information;
- 3 the ability to understand and appreciate how the information applies to the patient's own situation;
- 4 the ability to reason logically and weigh the information when considering the treatment options.

Patients who lack capacity to decide are patients who are 'deemed incapable of making a reasonable assessment of their interests in respect of a decision or situation at issue' (KNMG 2004). Lack of capacity relates to the patient's decision-making skills depending on the choices or decisions made in a certain context. A guide has been developed for the purpose of assessing capacity to decide (KNMG 2004).

2.6 Written living will

In the event the patient no longer is capable of making a reasonable assessment of his interests on the matter (KNMG 2004), he may have declared in writing at the time he still had decision-making capacity⁶ that he has decided against all forms or specific aspects of treatment, nursing and care for a future situation. In principle the care provider has an obligation to comply with such a written declaration or prohibition of treatment. The care provider may only disregard it if he has 'valid reasons' for doing so. Valid reasons may entail that the care provider doubts the authenticity, the signature or contents of the declaration. New developments and medical advancements may also have occurred since the declaration was drawn up, on account of which the care provider may reasonably assume that the reason for the patient drawing up the declaration has been rendered invalid. The care provider always interprets the written living will [which is also known as an advanced directive or advance care plan] in light of the intention of the individual who has drawn up the living will (the patient) Hertogh 1995), and preferably does in consultation with the representative(s).

⁵ In this guide the committee uses the term 'care provider' in accordance with the Medical Treatment Contracts Act as a generic term for physicians, nurses and carers.

⁶ The use of 'he' in this document should also be interpreted as 'she'.

2.7 Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation 2002).

Given the fact that consistently choosing not to eat and drink irrevocably leads to death, the committee regards the provision of care to the individual who has made this decision as a form of palliative care, even if the individual was not suffering from an immediate life-threatening illness at the time the decision was taken.

3 / Empirical data

This chapter describes the pathophysiological, physiological and clinical consequences of choosing not to eat and drink and discusses data from the literature relating to the practice of consciously choosing not to take food and fluids. Descriptive studies were examined (Ganzini 2003, Chabot 2007, Van der Heide 2012-I and II) in addition to publications describing case histories (Eddy 1994, Quill 2000-I, Koopmans 2004, Chabot 2007, Berry 2009, Aarnhem 2011-I and II, Koopmans 2012, Quill 2012).

3.1 The pathophysiological and clinical consequences of stopping eating and drinking

The body derives energy from burning carbohydrates and fats. The most important sources of energy in the body cells are glucose and free fatty acids. Under normal circumstances glucose is the most important fuel for most cells.

During the first 24 hours of strict fasting the liver releases glucose by breaking down glycogen (glycogenolysis) (Kerndt 1982, Owen 1983). This source, however, is rapidly depleted. The most important energy sources thereafter are:

- ▶ glucose formed in the liver from the conversion of amino acids, lactate and pyruvate (gluconeogenesis);
- ▶ ketone bodies (acetone, acetoacetate and beta-hydroxybutyrate) formed by breaking down free fatty acids; after a while these bodies become the most important source of energy for the brain.

Body proteins in the muscles and in the liver are eventually also broken down to maintain blood glucose levels and thus the energy supply to the brain. When tapping into the muscle protein reserves, the body will further weaken.

Strict fasting and drinking very little or nothing at all can often be tolerated well due to three factors:

- 1 When fat is burned, ketone bodies are formed, which have an analgesic effect in animal experiments.
- 2 After a few days a state of well-being regularly occurs under the influence of morphine-like substances (endorphins) produced by the body during strict fasting.
- 3 In the event of a low fluid intake, progressive renal impairment eventually occurs, which is accompanied by drowsiness. This is often experienced as a pleasant sensation.

The hunger pangs vanish after a few days provided the patient does not take in carbohydrates (in soft drink or in fruit, for instance).

If a patient with a life-threatening illness consciously chooses not to eat and drink, other factors additionally come into play. In connection with the illness the so-called anorexia cachexia syndrome may develop to a greater or lesser extent (depending on the nature of the illness and life expectancy). The syndrome is characterised by the combination of anorexia (often accompanied by quickly feeling satiated), the loss of muscle mass, weakness and cachexia (extreme weight loss). The increased production of inflammatory mediators (cytokines) plays a role here. Characteristically (contrary to the situation during fasting), the loss of protein and muscle mass occurs at an early stage.

Only two studies have been published on the effect of discontinued fluid intake in healthy people (Phillips 1984, Terman 2006). During the first study seven healthy older men (average age 70) were compared with a group of seven healthy young men (20-30 years of age) who were not given anything to drink under laboratory conditions for 24 hours (Phillips 1984). The group of older men were found to suffer far less from thirst (despite a sharper rise in their serum sodium levels) and a dry mouth. Furthermore, after 24 hours they replenished the shortage of fluid less quickly than the younger men. An explanation may lie in the fact that older people have a higher threshold for triggering the sensation of thirst, the mechanism for which is unknown.

The second study describes the findings relating to a healthy male aged 65 who ate nothing for four days and only drank around 40 ml a day (Terman). While he scarcely felt hungry, he did feel thirsty which he found an unpleasant sensation (rated as five on a scale of zero to ten). Thirst was manageable thanks to good mouth care. He described a not unpleasant ‘dulling of mental functioning’ after a few days, which he attributed to the production of ketone bodies.

No further literature was found concerning the clinical consequences of consciously choosing not to take fluids. It is often assumed that an increased serum sodium level induces thirst. A study conducted among terminally ill patients (whose life expectancy was 2 to 35 days) who no longer drank fluids as part of the dying process has shown that the serum sodium level usually is normal (Vullo-Navich 1998). While the patients with increased serum sodium levels indicated that they were experiencing slightly more discomfort than patients with normal serum sodium levels, the difference was marginal. In these terminally ill patients there was no difference in the level of patient comfort/discomfort experienced between patients who drank less than 500 ml a day and those who drank more than that amount. It is not known to what extent these data apply to patients with a longer life expectancy. Research and experience in caring for terminally ill patients strongly suggests that good mouth care (see also Section 5.5.3) can largely help eliminate the feeling of thirst or a dry mouth (Printz 1992, McCann 1994, Vullo-Navich 1998, Van der Riet 2006, De Nijs 2010).

Once a patient has consciously chosen not to drink fluids, urine production will eventually fall to a minimum level, the amount of stool passed will decrease and mucus secretion in the respiratory tract will be reduced. Based on research (Chabot 2007), in the event of strict water fasting the patient is likely to die within 18 days (see table 3.4). Death is thought to be caused by disruption of the transport of sodium and potassium across the membranes of the heart cells, resulting in cardiac arrest (ventricular fibrillation) and the patient’s acute death.

3.2 Epidemiological data

In 1997 an estimation was published of the frequency of deciding against the artificial administration of food and fluids among patients at the end of life in the Netherlands (Van der Heide 1997). Eight per cent of all deaths were found to have been preceded by a decision not to take food and fluids. However, the patients in three quarters of these cases were those who had impaired or completely lacked capacity to decide. The percentage found (8%) therefore is an incorrect estimation of the number of deaths in which the patient **consciously** chose not to eat and drink.

Ganzini carried out a survey among 307 nurses in Oregon, the United States of America (Ganzini 2003). Among the respondents, 102 indicated that in the last four years they had cared for a patient in a hospice who had consciously chosen not to eat and drink. See table 3.1 for specific patient characteristics.

For the first time in 2007 a frequency estimation was published of the annual number of deaths in the Netherlands among patients who had consciously chosen not to eat and drink (Chabot 2007). This occurred approximately 2,800 times a year and accounted for 2.1% of all deaths in the Netherlands in the years 1999-2003. Based on a nationwide sample, confidants who had been involved in the process surrounding a patient’s conscious choice not to eat and drink were traced (n=97). See table 3.1 for specific patient characteristics.

In a factor analysis the reasons for deciding to stop eating and drinking were broken down into the following four groups:

- 1 Somatic reasons (pain, breathlessness, nausea/vomiting and total body weakness/fatigue).
- 2 Dependence (invalidity arising from difficulty in walking, blindness or deafness, inability to look after oneself, incontinence or fear of incontinence, being a burden to others or fear thereof, and/or the loss of dignity or degradation).
- 3 Demoralisation (dejection, loneliness and/or a perceived pointlessness of existence);
- 4 Controlling the time and place of death (the wish to control death, the desire to die at home and/or being finished with life).

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

Almost half of the deceased patients in Chabot's study had made a request for euthanasia that had been turned down. According to the confidants, the physicians' most important reasons for doing so were that the patient was not terminally ill or was not suffering from an incurable illness (21%), the patient was not suffering from an illness (4%), the patient was not experiencing unbearable or lasting suffering (26%), fear of the legal consequences (17%) and personal beliefs (20%).

A Mortality Survey for 2010 similarly showed that almost half of those who had consciously chosen not to eat and drink had made a request for euthanasia that had not been granted (Van der Heide 2012-I). Van der Heide et al. arrived at a lower frequency estimation of the number of people that had died as a result of choosing not to eat and drink, namely 600 a year, equating to 0.4% of all deaths in the Netherlands in 2010. See table 3.1 for specific patient characteristics.

However, Chabot's study and the Mortality Survey are difficult to compare on account of the fact that the information was derived from different types of respondents (confidants in Chabot's case and physicians in Van der Heide's case). Van der Heide's study may lead to an underestimation of the frequency of such deaths, among other things in that it only relates to the cases in which a physician was aware of the patient choosing not to eat and drink. The confidants in Chabot's study may in some cases have misconstrued stopping eat and drinking in cancer patients as a conscious intention to hasten the end of life. His frequency estimation may therefore be slightly too high. After adjustment for this factor,⁷ the estimations in Chabot's study are still four times higher than those in the Mortality Survey (1.7% and 0.4% respectively).

In the field study (a component of the second evaluation of the Termination of Life on Request and Assisted Suicide Act (abbreviated to the Euthanasia Act), 45% of GPs, 57% of geriatric care specialists and 42% of medical specialists had occasionally treated a patient who had intentionally ended his life by stopping eating and drinking (Van der Heide 2012-II). A number of GP respondents (n=440) who had treated a patient who had died after having consciously stopped eating and drinking (no question of anorexia in a terminally ill patient) were invited to answer questions about the most recent case. The patient data derived from the relevant case (n=101) are shown in table 3.1. The estimated life expectancy in 34% of the cases was less than four weeks, in 31% of the cases one to six months and in 35% of the cases six months to more than a year. In 95% of the cases the GPs had assessed the patient as having capacity to decide. In 26% of the cases the GP had not been informed of the decision. Among the physicians, 94% were sympathetic to the patient's decision. In 18% of the cases they indicated that they had suggested the option to stop eating and drinking to the patient.

The main reasons for consciously choosing not to eat and drink (categorised in the same way as in Chabot's study) are stated in table 3.2.

The role of GPs and those close to the patient in offering guidance is shown in table 3.3. This shows that 31% of the GPs in the study had no guiding role in cases where patients had consciously chosen not to eat and drink. In 31% of the cases, no persons close to the patient had been involved.

⁷ Personally communicated by Boudewijn Chabot, May 2013.

Table 3.1 Research results - Ganzini, Chabot and Van der Heide

	Ganzini 2003	Chabot 2007	Van der Heide 2012-I (Mortality Survey)	Van der Heide 2012-II* (Field Study)
Respondents	Hospice nurses	Confidants	Physicians	GPs
Frequency estimation of making a conscious choice not to eat and drink	-	2,800 (2.1%)	600 (0.4%)	-
Number of respondents	102	97	18	101
Patients				
Female	54%	60%	51%	-
Age	74 (average)	80% aged > 60	96% aged > 65	94% aged > 65 84% aged > 75
No partner	48%	70%	-	-
Primary diagnosis	60% cancer, 16% cardiovascular diseases and 23% nervous system diseases	40% incurable illness, 32% severe somatic or psychiatric disorders, 28% deficiencies but no illness	15% cancer 14% cardiovascular diseases, 16% nervous system diseases and 54% other/unknown	27% cancer, 39% a physical condition other than cancer, 21% early-stage dementia, or a psychiatric disorder, 24% no serious physical condition or psychiatric disorder**

* This is a select group of patients in Van der Heide's study, in which only the GP was involved and where there was no question of anorexia in a terminally ill patient.

** Multiple answers may be given.

Table 3.2 Patients' reasons for hastening the end of life by stopping eating and drinking (Chabot 2007 and Van der Heide 2012-II)*

	Chabot 2007 n=97	Van der Heide 2012-II n=101
Somatic		
Weakness or fatigue	53%	58%
Pain	38%	17%
Breathlessness/fear of suffocation	10%	9%
Dependence		
Dependence	38%	33%
Being a burden to others	22%	15%
Invalidity (bedridden/blind)	23%	31%
Loss of dignity	56%	28%
Demoralisation		
No purpose in life	43%	38%
Loneliness	11%	26%
Depressed/dejected	10%	13%
Control over death		
Completed life	59%	40%
Loss of control	25%	26%

** Multiple answers may be given.

Table 3.3 The role of GPs and the involvement of those close to the patient in the process of stopping eating and drinking (Van der Heide 2012-II)

GP's guiding role:*	
During the preparatory phase	21%
During implementation (no palliative sedation)	29%
Palliative sedation until death	29%
None	31%
Those close to the patient:*	
During the preparatory phase	44%
During the implementation phase	53%
No	31%
Does not know	3%

* Multiple answers may be given.

3.3 Course

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

In Chabot's study (2007), the time it took patients to die is shown in table 3.4. It is uncertain whether patients who died within seven days (n=40) died of the consequences of choosing not to eat and drink, or of the consequences of an illness. For scientific reasons, they have therefore been excluded from the frequency estimation. This means that the cohort described in table 3.1 (n=97) only consisted exclusively of patients who lived longer than six days after having stopped eating and drinking. Irrespective of the nature of the illness the median duration until death was 15 days, in other words 50% died within 13 days.

Table 3.4 Length of time until death

Duration from not drinking until death	In patients with an incurable or serious illness	In patients not suffering from an incurable or serious illness	Total
<7 days	40	0	40
7-9 days	19	5	24
10-12 days	17	4	21
13-15 days	12	10	22
16-18 days	3	1	4
19-30 days*	12	3	15
31-60 days*	6	2	8
<60 days*	1	2	3
Total	110	27	137

*Because these patients continued to drink more than 50 ml daily, they were unlikely to die within 18 days.

Chabot (2007) has broken down the dying process into three phases. During the first phase (3 to 4 days) the patient abruptly or gradually stopped drinking fluids. The middle phase varied in length. During this period diffuse pain complaints or symptoms of delirium sometimes occurred. Painkillers or sleeping pills were the most frequently prescribed pain relief medication. During this phase some people again began drinking fluids. Thirst was not a major complaint and in most cases could be prevented or reduced by providing good mouth care. The final phase lasted several days and was comparable to the dying phase of a patient suffering from an incurable illness.

Ten per cent of the confidants indicated spontaneously that the dying process had proceeded painfully or in an undignified manner; forty per cent indicated spontaneously that it had proceeded peacefully, with no pain, or in a dignified manner. Other individuals close to the patient provided no spontaneous information about the course.

4 / Legal and ethical aspects

4.1 Introduction

This chapter begins by examining a patient's choice not to eat and drink. The patient's right to information, consent and the role of a living will [which is also known as an advance directive or advance care plan] are subsequently discussed, followed by an explanation of the position of the patient's representative. Lastly, support and guidance are covered in relation to the following aspects:

- 1 decision-making and actions by care providers;
- 2 good practices in the provision of care;
- 3 assisted suicide;
- 4 conscientious objection by care providers.

4.2 The patient's choice

Consciously choosing not to eat and drink to hasten the end of life is a choice each and everyone can and may make for themselves. This decision does not require the individual to consult with a physician, a nurse, carer or any other party. The choice to hasten the end of the life is a drastic choice for both patients and those close to them. It is a choice between a life deemed unacceptable by the patient or the patient's own choice to die. The patient's considerations may entail that it is pointless to continue living, that the quality of life is insufficient and/or that he wishes to control the manner and moment of death (Chabot 2007, Ganzini 2003, Van der Heide 2012-II). Death is regarded as the least worst option. It is a choice the patient may reconsider.

4.3 The right to information, consent and the role of a written living will

Under the Medical Treatment Contracts Act, a patient has the right to receive clear information from the physician about his medical condition, the prognosis and treatment options (see section 2.4). Should the patient not grant consent to being artificially administered food and fluids or offered food and drink, care providers may not provide this form of treatment, nursing or care.

The patient may furthermore have declared in writing that he has decided against all forms or specific aspects of treatment, nursing and care for a future situation. The prohibition of treatment may relate to offering food and drink or artificially administering food and fluids. If the patient has such a written living will, it will help provide care providers insight into the patient's carefully considered decision-making process in choosing to stop eating and drinking. However, is not necessary for a written living will to have been drawn up in order to implement the patient's conscious decision not to eat and drink.

If a patient has lost capacity to decide, the care provider must continue to respect the prohibition of treatment, unless there is a valid reason for departing from it (see Section 2.6 and Chapter 6).

4.4 The position of the patient's representative

In some cases patients will have appointed a medical proxy (see Section 5.4.4). The patient's rights pass to his representative or medical proxy if the patient loses capacity to decide during the process.

The Medical Treatment Contracts Act stipulates that the following parties qualify as the patient's representative (in hierarchical order): the legal representative (curator or mentor), or failing this a medical proxy, or failing this a spouse, partner or life companion, or failing this a parent, child or sibling (Section 7:465 of the Dutch Civil Code). The patient's representative (this is usually the patient's partner or child in practice) is deemed to take decisions concerning care and treatment for the patient the moment the patient becomes incapable of doing so himself.⁸ This therefore includes decisions about offering or administering food and fluids if, after having consciously chosen not to eat and drink, the patient has lost capacity to decide in the course of the process (due to delirium, for instance) and asks for something to drink. In this case the representative is deemed to take decisions in line with the patient's conscious decision not to eat and drink. The care provider should observe the practices of a 'good care provider' (see Section 4.6) and act in line with the patient's original decision. In this situation the living will referred in Section 4.3 would be helpful for both the representative and the care provider.

4.5 Decision-making and actions by care providers

The care providers are entrusted with the following tasks in sequential order:

- 1 providing information;
- 2 preparing the patient;
- 3 providing guidance to the patient.

Sub 1 Providing information

Should the patient raise the matter of wanting to hasten the end of life by consciously choosing not to eat and drink, the care provider has a professional duty to enter into dialogue with him, during which the request for assistance will also be explored (KNMG 2011). During that discussion the physician explores the patient's feelings, ideas and considerations. To that end the KNMG guides entitled *Tijdig spreken over het levenseinde* ('Talking about the end of life in a timely manner') will be helpful for patients and physicians alike (KNMG 2012-I and 2012-II).⁹

A patient who consciously chooses not to eat and drink to hasten the end of life may seem depressed. This does not mean to say that the patient automatically qualifies as lacking capacity to decide. Depressed patients likewise may consciously choose not to eat and drink to hasten the end of life. When exploring the patient's feelings, ideas and considerations underlying his intended decision to stop eating and drinking, the care provider should examine the possibility that the patient may be suffering from depression and consider treatment for the condition. In that case the care provider may consult a psychiatrist. However, the patient has the right to decline a diagnosis and any depression treatment. The patient's right does not discharge the physician from his duty to continue to act as a good care provider during the process of choosing not to eat and drink.

The care provider should inform the patient as thoroughly and objectively as possible about the expected course, the advantages and disadvantages, as well as the anticipated problems, particularly where young patients are concerned. The care provider must advise patients under 60 years of age who are not suffering from a life-threatening illness against choosing not to eat and drink to hasten the end of life.¹⁰ Patients over the age of 60 need not be dissuaded from consciously choosing not to

⁸ This excludes euthanasia and assisted suicide because requests for these procedures are reserved exclusively for the patient, the termination of life is irreversible and assisted suicide is not an ordinary medical procedure (KNMG 2004).

⁹ Guides are available for both care providers and patients. They can be downloaded from www.knmg.nl/spreken-over-levenseinde (in Dutch).

¹⁰ Almost all patients referred to in the literature were over 60 or suffered from a life-threatening illness. Younger patients in a good overall state of health will probably be unable to go without drinking because they have a more intense thirst sensation than older people and their kidneys are more capable of retaining fluid.

eat and drink on account of the fact that they are not suffering from a life-threatening illness or that they are still in a good state of health.

The provision of information may also consist of highlighting the importance of good and reliable information, where it can be obtained and sharing the care provider's experience in dealing with other patients. It would therefore be recommended to consult experts, including those in the field of mental health care. During the discussion other options for voluntarily terminating life in a humane manner should be pointed out to the patient. Discussion of these options, however, falls outside the scope of this guide.

Though patients often discuss their intention at length with those close to them, they must sometimes also be encouraged to do so. While hastening the end of life by consciously choosing not to eat and drink, strictly speaking, does not require support from care providers, the patient must receive the proper care at all times. The patient must be dissuaded from stopping eating and drinking, however, without proper preparation and support from care providers (Chabot 2013, Quill 2012, Schwarz 2007). This is because the patient will grow weaker, will need help and the symptoms arising as a result of not taking in food and fluids are unlikely to be adequately alleviated without assistance. Alongside the support, care and nursing provided by those close to the patient, volunteers, carers and/or nurses, medical supervision is strongly recommended in order to achieve the patient's goal in the best possible manner. Whilst caring for a patient generally means ensuring they eat enough food and drink enough fluids, this no longer is the case. Any suffering that may occur must be relieved to the best possible extent by, for instance, providing mouth care, sleeping medication and, where necessary, pain medication (see Chapter 5).

The patient's decision to stop eating and drinking may relate to a request for euthanasia that has been turned down (see Chapter 3). If the patient takes the decision to stop eating and drinking simply because he is angry about the rejection of his request for euthanasia, the conflict could shift to the issue of whether or not to drink fluids. Disappointment and in some cases anger can make the process preparations and guidance arduous for both the patient and the care providers (Van Aarnhem 2011-I and 2011-II). Therefore it is vital to continue to clearly communicate with the patient to explain why the request for euthanasia cannot be complied with. In such situations the committee assumes that the request for euthanasia cannot be granted because the due care criteria for euthanasia have not been fulfilled. In all other cases, please refer to the KNMG's position on euthanasia and professional responsibility (see Appendix 1).

In some cases patients may have a sustained longing to die and will not raise the option of choosing not to eat and drink of their own accord. Physicians and other parties may in such cases point out this option to patients when exploring their request for assistance.

When dealing with patients who have indicated that they no longer wish to eat and drink to hasten the end of life, care providers may doubt the patient's capacity to decide. Patients, however, do not need to prove that they do have capacity to decide. The physician is the designated party who must plausibly demonstrate that patients are no longer deemed capable of making a reasonable assessment of their interests in the matter (see Section 2.5).

Sub 2 Preparing the patient

If, after the physician has explored the patient's request for assistance and provided information, the patient continues to have a sustained longing for death and consciously wants to stop eating and drinking, the physician should proceed to make preparations (see Chapter 5). A sustained longing for death may come to light during the care provider's conversations with the patient. This may but need not be supported by a written living will (prohibition of treatment, see Section 5.4.4). By writing down which life-sustaining or other actions/treatments may not/no longer be carried out, the patient

explicitly reconfirms his own choice to end life. In many cases the prohibition of treatment will state that the patient has neither granted consent to offer food and drink, nor to administer food and fluids. Care providers must respect the patient's decision and prepare the patient for the various phases lying ahead.

Sub 3 Patient guidance

By providing guidance, care providers and those close to the patient can help relieve the patient's suffering and any complications that may arise as a result of choosing not to eat and drink. To ensure the continuity of care, good collaboration is vital. It is key to ensure good coordination among all parties, by sharing information and ensuring regular communication among all care providers, as well as with the patient and those close to the patient. It would be prudent for the physician to consult, collaborate with and seek advice from experts, such as palliative care consultation teams, nurses, carers or geriatric care specialists. Should the care provider doubt his own level of expertise he must, in accordance with the professional standard, consult the appropriate expert in a timely manner. The relevant expertise is accessible and available to all care providers.¹¹

A lack of cooperation and coordination can have major consequences not only for patients and those close to them but also for care providers. It is imperative therefore to ensure that clear agreements are made between all the parties concerned. Care providers must record information relating to the patient in the patient's file. The attending physician must ensure that a proper handover takes place to the replacement physician and the other care providers involved, especially for the evening, night and weekend hours. They must be readily accessible and available for the patient. Nurses and carers must equally ensure a proper handover to their colleagues.

4.6 Good practices in the provision of care

Section 453 of the Medical Treatment Contracts Act states the following: 'Care providers must perform their tasks with due regard for the care provided by a good care provider and act in accordance with the responsibility they bear pursuant to the professional standard to which care providers are subject'. The professional standard for physicians, nurses, carers and other care providers includes being mindful of the patient's overall well-being and providing guidance to patients who have existential questions arising from their illness or from an accumulation of old-age related complaints (KNMG 2011). This includes demonstrating compassion and offering palliative care, terminal guidance and emotional comfort.

'A good care provider' is also expected to ensure that the representative or family caregivers serve the patient's best interests and, in the event of doubt, must raise and discuss the issue with them.

4.7 Consciously choosing not to eat and drink to hasten the end of life in relation to suicide/assisted suicide

There is no legal definition for suicide. This is associated with the fact that suicide is not a criminal offence. In everyday speech, suicide is taken to mean that 'the victim has committed an act for the express purpose of taking one's own life (literal translation of CBS Statistics Netherlands' definition). This definition has been maintained in this guide.

¹¹ For palliative care consultation teams, see www.iknl.nl.

While suicide is not a criminal offence in the Netherlands, the opposite applies to offering assistance in suicide. ‘A person who intentionally incites another person to commit suicide, a person who helps another person to commit suicide, or provides him the means to do so will be punished if suicide follows’ (Section 294(1)(2) of the Dutch Penal Code (*Wetboek van Strafrecht*). The law only makes an exception to this prohibition for physicians. In assisted suicide (just as in euthanasia) physicians are not liable to prosecution if, when implementing assisted suicide, they have acted in accordance with the criteria laid down in the Termination of Life on Request and Assisted Suicide Act (Euthanasia Act), and they report it (KNMG 2011).¹²

Case law, however, shows that not every form of assisted suicide - performed outside the scope of the Euthanasia Act - is a punishable offence, or, put differently, that not all acts qualify as assistance within the meaning of the Act.¹³ The Supreme Court of the Netherlands (*Hoge Raad der Nederlanden*) ruled that providing information on suicide, holding discussions on this topic and offering moral support in suicide cases are not criminal offences (Mulder-Weiss ruling, Supreme Court of the Netherlands, 5 December 1995). However, providing instructions, giving an order or taking over control when a person commits suicide do qualify as punishable assistance in suicide (Muns ruling; Supreme Court of the Netherlands, 22 March 2005).¹⁴

Consciously choosing not to eat and drink might be interpreted as suicide. The committee wishes to underline, however, that consciously choosing not to eat and drink and suicide cannot be deemed equivalent because there may be relevant differences between the two. Suicide is associated with an active, violent, lonely and often impulsive act.

In consciously choosing not to eat and drink the patient is attempting to hasten the end of life. While it is a choice for death, it differs essentially from suicide, also from a legal point of view. Consciously choosing not to eat and drink is comparable to refusing antibiotics, artificial respiration or palliative chemotherapy, which refusal will result in death. This is not regarded as suicide but rather as the patient exercising his right of self-determination, particularly the right to refuse care. While it may result in the end of life, or hastening it, it cannot be considered the equivalent of suicide.

Consciously choosing not to eat and drink usually is a process in which those close to the patient (as well as care providers) are involved in the preparatory phase and in offering guidance. An essential difference with suicide is that a patient who consciously chooses not to eat and drink during the early and middle phases can choose to reconsider that decision. The core of the matter lies in the fact that the patient does not grant consent for providing life-sustaining care (including offering food and drink and artificially administering food or fluids), but does grant consent for relieving complaints. Refusing treatment is a right to which the patient is entitled, even if this in effect hastens the end of life.

¹² If a physician provides assistance within the framework of the Euthanasia Act in a suicide case, he offers the patient a lethal drink which the patient self-administers, after which the patient dies. When performing euthanasia the physician gives the patient a lethal injection.

¹³ See for example 5 December 1995, Dutch Case Law NJ 1996, 322 (with commentary from A.C. 't Hart); Supreme Court of the Netherlands, 22 March 2005, GJ 2005, 61 (with commentary from W.L.J.M. Duijst-Heesters) and Supreme Court of the Netherlands, 18 March 2008, Dutch Case Law NJ 2008, 264 (with commentary from T.M. Schalken). See also Chabot 2012, p. 219-229, for the types of assistance in suicide which are deemed/not deemed a criminal offence.

¹⁴ In the Hilarius ruling (Supreme Court of the Netherlands, March 2008, National Case Law Number LjN: BC4463) the Supreme Court found that actively providing medication as a method of suicide is a criminal act insofar as it enables or makes it easier for another person to kill himself. In this ruling the Supreme Court interprets the aspect of ‘assistance’ in suicide more broadly than prior to that date since suicide is no longer required to have taken place in order for the act to be punishable. When responding to Parliamentary questions raised on account of information posted on the NVVE’s website about lethal substances and methods, the Minister of Justice and the Minister of Public Health, Welfare and Sport argued that comparison with the Supreme Court’s ruling in the Hilarius case was not deemed relevant as numerous factors depended on the circumstances surrounding the case. In this particular case medication had actively been supplied. The government ministers furthermore referred to the answers previously given to questions concerning recommended methods of suicide (Lower House of Parliament 2009/10, Appendix 1469). These answers are based partly on the Mulder-Meis and Muns rulings (Lower House of Parliament 2007/08, Appendix 2339).

Acts performed by care providers while caring for a patient who has consciously chosen not to eat and drink to hasten the end of life are aimed to adequately and proportionately relieve the patient's suffering. This is not associated with suicide and therefore is not punishable pursuant to Section 294 of the Dutch Penal Code. Medical supervision, nursing and care are provided in the context of a patient who has granted consent for that specific form of care. From a legal perspective, failure to offer such assistance may even be qualified as abandoning a person in need of help (Section 255 of the Dutch Penal Code). A patient who chooses not to eat and drink will die a natural death. Notice of the patient's death is not required to be reported to the municipal forensic pathologist.

4.8 Conscientious objection by care providers

It is widely acknowledged in the health care sector that care providers may have conscientious objections to performing certain acts (AVVV)/Nieuwe Unie'91/KNMG 2006, V&VN Dutch Nurses' Association 2008). The unwillingness to be involved in the preparation or implementation of termination of life on request or assisted suicide is illustrative of such a situation. In cases where a patient has consciously chosen not to eat and drink, unlike euthanasia or assisted suicide (as defined in the Euthanasia Act), there is no direct link between acts performed by the care provider and hastening the end of life. However, it might be argued that the care provider facilitates the patient in hastening the voluntary termination of life. This may give rise to conscientious objection among care providers.

If physicians, nurses or carers are involved in the patient's intention to consciously choose not to eat and drink to hasten the end of life, this may present a dilemma. The patient's choice may seriously conflict with the care provider's personal beliefs or personal norms and values.

Caring for a patient generally means ensuring that the patient eats enough food and drinks enough fluid. Eating and drinking extends beyond nutrition. Eating and drinking denotes life as well as living life together (V&VN Dutch Nurses' Association, 2006). To stop offering food and drink because the patient has chosen to hasten the end of life may lead care providers and those close to the patient to believe that the care offered is poor. The care provider may also have conscientious objections in that providing assistance partially facilitates hastening the voluntary termination of life. Nevertheless, the care provider has a duty to act as a good care provider, even if he disagrees with a choice made by the patient that will lead to health problems and/or hasten the end of life.

Consciously choosing not to eat and drink requires a continuous effort on the part of the patient, with which he confirms his wish to die. If care providers are involved in this process, intensive care is required. If a care provider has conscientious objections to providing such care, he may assign the care for the patient concerned to a colleague care provider. Carers and nurses who have conscientious objections must communicate this to their supervisors or the client accordingly (V&VN Dutch Nurses' Association 2008). A patient may, however, not be deprived of the care required when consciously choosing not to eat and drink. A care provider who invokes conscientious objections should, as befits a good care provider, provide care until such time as a colleague takes over this duty.

5 / Care and guidance by professionals, volunteers and those close to the patient

5.1 Introduction

This chapter discusses immediate care and guidance for patients who consciously choose not to eat and drink.

Depending on where the patient is staying (in most cases at home, in a nursing home or a hospice) and the circumstances, the following people may be involved in caring for and providing guidance to the patient:

- ▶ physicians, in practice mainly GPs, geriatric care specialists and hospice physicians;
- ▶ nurses and/or carers;
- ▶ volunteers;
- ▶ spiritual counsellors.

Alongside the above parties, family members and/or other confidants (collectively referred to as those close to the patient) play a crucial role in the provision of care and guidance. The role of those close to the patient is initially discussed below, while the remaining sections of this chapter subsequently examine the professional aspects of providing care and guidance. The organisation and coordination of care are crucial in this process. Professionals, volunteers and those close to the patient share responsibilities; the professionals may be expected to supervise the process.

5.2 The role of those close to the patient

Research has shown that those who wish to hasten the end of life by consciously choosing not to eat and drink usually discuss their wish with one or more confidants or those close to the patient prior to consulting a physician (Chabot 2007). Those close to the patient¹⁵ are emotionally attached to the individual. This means they are in the best position to judge what matters keep a person alive and what his motives are for wanting to die. The will to live is nurtured by their bond with intimate acquaintances. They can make the difference between whether the patient wants to live or would rather die.

The talks between the patient and those close to him by no means always lead to a request to the physician for assisted death. Should this be the case, it may take the form of a request for euthanasia or raise the question of palliative care in the event the patient has chosen not eat and drink. The role of those close to the patient as an intermediary between the patient and the physician is crucial in this process. They can provide insight into the remaining options or limitations. Moreover the patient may have second thoughts about embarking on this difficult pathway if his intimate acquaintances are unwilling to provide care and support, or incapable of doing so. Objections to the patient's wish to die raised by those close to the patient can play an important role in the decision-making process, during which the physician can sometimes serve as a mediator.

If the patient's wish to die is implemented, those close to the patient have a crucial role in day-to-day proceedings. They often are almost constantly at the patient's bedside, taking turns to do so, and help provide general and mouth care. They also serve as the care providers' eyes and ears in judging whether symptoms and complaints are sufficiently under control, and provided they have received all the required information, may be the first to observe signs of the onset of delirium.

¹⁵ Often a person close to the patient serves as the 'central contact' who is more closely involved in the decision-making process than the others. We have used the plural 'those close to the patient' here given that the wider circle serves as a sounding board for the central contact and moreover will be called upon to help care for the patient after a decision has been taken.

As a care provider involved in the process, it is vital to ensure a good working relationship and good coordination with those close to the patient (see also Section 4.5(3)).

This guide is designed primarily for physicians, nurses and carers but may also be read by those close to the patient. They may, however, have difficulty in understanding the medical terminology used. Those close to patients can find information in the book written in Dutch entitled *Uitweg* (literally translated 'Way Out') to help them provide the best possible care, support and guidance to the patient during the process of consciously stopping eating and drinking (Chabot en Braam 2013).

5.3 The various phases in the process

The required care and guidance are described for each phase (see also Section 3.3).

- 1 The preparatory phase
- 2 The implementation phase
 - the first phase (usually a few days), during which the patient immediately or gradually stops eating and drinking;
 - the middle phase (the duration may vary significantly, depending in part on the patient's physical condition at the start of the process and the pace and extent to which food and drink are gradually reduced.
 - the dying phase (the final days before and shortly after death).

These phases cannot be strictly separated from each other in practice, with each phase often gradually transitioning into the next. A number of preparations may not yet have been completed or may not even have begun if the patient has already stopped eating and drinking. The care provider may sometimes only be involved if the patient has already stopped eating and drinking. In this situation, all aspects in the preparatory phase discussed below will only take place during the implementation phase.

5.4 The preparatory phase

The preparatory phase involves the following:

- ▶ providing information, preparing and supporting the patient and those close to the patient;
- ▶ adapting medication;
- ▶ organising and coordinating care;
- ▶ drawing up a written living will and appointing a legal representative.

Clearly, not all aspects stated below will need to be addressed during one conversation. A number of aspects do not apply in specific situations while other aspects cannot (yet) be properly discussed and/or should preferably be discussed at a later stage.

5.4.1 Providing information, preparing and supporting the patient and those close to the patient;

The physician primarily conducts the preparatory discussion, preferably together with a nurse and/or carer.

This discussion covers the following matters:

- ▶ the patient may quickly stop eating and drinking, the hunger pangs will usually vanish within a few days;
- ▶ the patient may choose to either gradually or abruptly stop eating and drinking (see 5.5.1);
- ▶ if the patient feels thirsty, normally this can largely be relieved by providing good mouth care;
- ▶ during the process the patient will always have scope and an opportunity to reconsider his decision not to eat and drink;

- ▶ most people die within one to two weeks after having eaten very little or nothing at all. The duration of this period is influenced by the patient's physical condition at the time he stops eating and drinking and by whether or not he continues to drink fluids. If the patient continues to take in fluids, the period until death may take several weeks to months;
- ▶ the care provider must advise patients under 60 years of age who are not suffering from a life-threatening illness against choosing not to eat and drink to hasten the end of life;
- ▶ there are other options for terminating one's life voluntarily;
- ▶ proper mouth care, sleeping medication and in some cases pain relief and sedatives are essential;
- ▶ a strongly fluctuating state of drowsiness will regularly occur, which will gradually intensify. This may be accompanied by confusion (delirium);
- ▶ discomfort and suffering cannot always be avoided even with maximum support;
- ▶ in some situations palliative sedation may be initiated, but only if a refractory symptom exists.

During the discussion the physician should gauge to what extent those close to the patient endorse the patient's decision. In some cases they may have difficulty in coming to terms with it. They may also harbour feelings of guilt, feel they have failed in their duty towards the patient, or fail to understand or feel angered by the patient's decision. It would be beneficial to raise these matters during the discussion, since the patient must receive the proper support and guidance from those close to him to ensure the process proceeds as smoothly as possible. Those close to the patient who express ambivalence or opposition will compound the process for all parties concerned. As discussed in Section 4.5, given that a request for euthanasia that has been turned down may complicate the process, it is essential to discuss the matter with both the patient and those close to the patient. The patient's request for euthanasia should be reconsidered if the patient has indicated that he actively wants to hasten the end of life and is experiencing unbearable and lasting suffering. It is important to discuss how those close to the patient and the care providers should respond if the patient requests something to drink despite his decision. In such situations the patient should be asked whether he is certain that he would like something to drink. If the patient answers in the affirmative and has capacity to decide on the matter, the request should always be complied with. After all, the patient must be given an opportunity to reconsider his request. A special situation arises if the patient is in a delirious condition and asks for fluid (see Section 5.6.5).

Attention must furthermore be given to the following:

- ▶ adjusting the bed and anti-decubitus mattress;
- ▶ the necessary mouth care products;
- ▶ the availability of a bedpan, urinal or incontinence products, the need/wish for a urinary catheter;
- ▶ giving an enema, if needed;
- ▶ where applicable: consult with the cardiologist about the need to switch off a pacemaker and/or ICD.

The following matters may also be raised during the discussion:

- ▶ financial/legal arrangements that still need to be made (such as a will, a payment authorisation, etc.);
- ▶ Other matters (relating to tangible and intangible matters) that still need to be arranged or finalised;
- ▶ saying farewell;
- ▶ the patient's wish for rites before and/or after death;
- ▶ the course of events after the patient's death (personal care, dress, open coffin viewing, etc.);
- ▶ the funeral service/cremation (format and arrangements).

In order to support the patient and those close to the patient, the following services may be approached:

- ▶ in a domestic environment:
 - Home Care nurses and/or carers (if desired, and if they are not yet involved);
 - home help and/or domestic assistance;
 - Palliative Terminal Care volunteers (VPTZ, www.vptz.nl), who are qualified and have been trained to sit with dying patients, assist with practical care, inform patients and offer them emotional support, perform occasional care tasks and recognise and report any changes in the care situation;
- ▶ a spiritual counsellor, who can play an important role if for example a patient has questions about the meaning of life or unfinished business, and who can provide guidance and support to those close to the patient, or help with any desired death rituals and can discuss the format of a cremation or funeral service. See also the spiritual care guideline issued by the Comprehensive Cancer Centre the Netherlands (IKNL, formerly the Association of Integrated Cancer Centres) (Leget 2010, www.pallialine.nl).

5.4.2 Adapting medication

The following points require attention where medication is concerned:

- ▶ Medication for which there is no longer an indication should be discontinued (these include statins, diuretics, antihypertensives, anticoagulants, antidiabetic agents and bisphosphonates). Only medication to relieve existing complaints, such as pain, breathlessness or nausea should be continued. If stopping medication induces withdrawal symptoms (opioids and benzodiazepines), the medication should be continued, particularly if it has been administered for a long time and/or in high dosages. Corticosteroids (prednisone or dexamethasone) should preferably be discontinued in view of their appetite stimulant effects, unless this medication is required to control pain or other symptoms. If the patient has used corticosteroids for a long time (>4 four weeks) or in high dosages (dexamethasone: >4 mg/daily, prednisolone: >30 mg/daily), they should be tapered off and discontinued within a few days to one week. These substances should in this case be administered subcutaneously.
- ▶ The medication should no longer be administered orally, particularly in the course of the process. Alternative routes of administration are set out below:
 - Rectal. A number of substances can be administered as a suppository. Some oral administration forms can also be given rectally. This applies, for example, to slow release morphine, slow release oxycodone and temazepam. Diazepam may also be given as rectol. In some cases rectal dosages will differ from dosages given orally. Objections to rectal administration include that it may be stressful to place seriously weakened patients in the required position for administration and that the substances will sometimes be discharged before they have been resorbed in the rectum.
 - Through the mucous membranes of the mouth and nasal cavity:
 - sublingual administration (underneath the tongue);
 - buccal administration (through the buccal mucosa);
 - oromucosal administration (through gum mucosa);
 - intranasal administration (through nasal mucosa).
 - Transdermal administration (as a patch);
 - Subcutaneous administration (underneath the skin). These substances can be administered as intermittent injections or through continuous subcutaneous infusion using a pump. This method involves subcutaneous needle insertion. In the event of intermittent administration, the appropriate person must self-evidently be available at the agreed time(s) to give the subcutaneous injection.
 - Intramuscular administration (in the muscle). This method of administration, however, is rarely or never necessary. An intramuscular injection can be painful. Almost all substances administered intramuscularly can also be administered subcutaneously. The subcutaneous route of administration is (strongly) preferred.

- Intravenous administration (through the blood stream): only if there is a central line (such as a PICC line, a subclavian catheter, a totally implantable administration system or a Hickman catheter). In other cases, subcutaneous administration is the preferred route.
- ▶ Furthermore the following medication should be prescribed, clearly explained and issued to the patient for self-administration as and when necessary (provided he has no cognitive problems):
 - sleep medication;
 - pain killers for acute pain;
 - if necessary: other medication for complaints that may arise in the short term (for example breathlessness, delirium or anxiety).

This medication must be taken on the basis of a medical indication.

The care provider makes clear agreements on, and documents what medication should be given and when, for which indication, and the required dosage and route of administration. See table 5.1 for a list of a number of commonly used substances and alternative routes of administration.

Table 5.1 Substances commonly used and non-oral routes of administration

Indication		Medication	Alternative route of administration
Pain	Maintenance treatment	Paracetamol	Rectal
		Slow release morphine or slow release oxycodone	Rectal
		Morphine or oxycodone	Intermittent or continuous SC or IV
		Fentanyl	Transdermal (patch)
		Buprenorphine	Sublingual, transdermal (patch)
	Break-through medication	Immediate release morphine	Rectal, SC or IV
		Immediate release oxycodone	SC or IV
		Fentanyl	Sublingual (Abstral®, Recivit®) Oromucosal (Effentora®, Breakyl®) Buccal (Actiq®) Intranasal (Instanyl®)
Nausea and vomiting	Metoclopramide	Rectal, SC, or IV	
	Domperidone	Rectal	
	Haloperidol	Buccal, SC or IV	
	Levomepromazine	Buccal, SC or IV	
Constipation	Bisacodyl	Rectal	
	Sodium Lauryl Sulfoacetate	Micro enema	
	Phosphate enema	Rectal	
Delirium	Haloperidol	Buccal, SC or IV	
Sleeping problems, anxiety and sedation	Temazepam	Rectal	
	Midazolam	Intranasal, buccal or SC	
	Lorazepam	Sublingual, SC or IV	
	Diazepam	Rectal or IV	
	Clonazepam	Sublingual, SC or IV	
	Levomepromazine	Buccal, SC or IV	

5.4.3 Organising and coordinating care

Clear agreements must be made on the following:

- ▶ the involvement of care providers and those close to the patient, and the division of tasks and responsibilities among them;
- ▶ how often and at what times care providers, volunteers and those close to the patient should be present. The fulfilment of these agreements depends on a) the patient's wish, b) the patient's physical condition (which will increasingly deteriorate), and c) the presence and willingness/ability of those close to the patient to provide care. In most cases, after several days someone (a person close to the patient, a volunteer or a care provider) will/must constantly be at the patient's bedside.
- ▶ the availability of care providers during and outside working hours.

Regardless of where the patient is staying, it is essential to ensure good communication and coordination among all parties. This implies the following:

- ▶ a proper handover within all the disciplines involved, where the continuity of care is guaranteed, including outside working hours;
- ▶ interdisciplinary consultation times and consultation with the patient and those close to the patient;
- ▶ a care plan must be drawn up;
- ▶ a clear report must be made of daily proceedings and the agreements made, preferably in a central file (in a domestic situation the care file maintained by the Home Care organisation) or in a care pathway.

5.4.4 Written living will and appointing a legal representative

It would be advisable (although it is not a requirement) for the patient to record the following in writing:

- ▶ that he has consciously chosen not to eat and drink;
- ▶ that he has no desire to be admitted to hospital or any other facility;
- ▶ that he has neither granted permission to offer food and drink, nor to artificially administer food and fluids;
- ▶ that he has decided against life-sustaining treatments (including cardiopulmonary resuscitation (CPR));
- ▶ how to act if he asks for something to drink in a delirious condition;
- ▶ who the patient's representative is if the patient loses capacity to decide.

Even though a written living will may be drawn up and recorded in writing by a person other than the patient, it must be personally signed by the patient. The patient may, if necessary, record the spoken text of the living will.

5.5 Implementation phase: first phase

In the early stages of the implementation phase the patient more or less gradually stops eating and drinking, usually over the course of a few days but may sometimes do so faster or more slowly. A start should be made with the general personal care of the patient (depending on the patient's physical condition) as well as with mouth care.

5.5.1 Reducing the intake of food and drink

The patient may in many cases soon or even immediately stop eating, particularly if his appetite has already decreased considerably. The hunger pangs (to the extent they occur) will generally vanish within a few days, provided that the patient does not consume carbohydrates (such as those in fruit, fruit or soft drinks).

No universal advice can be given for stopping drinking. Some patients want stop drinking quite abruptly, from one day to the next, whereas other patients prefer to reduce their fluid intake over the course of several days to the minimum amount (less than 50 ml) required for mouth care. There are also patients who may continue drinking more than 50 ml of water daily, in which case the process may take more, or much more, than two weeks.

This period will give the patient an opportunity to experience what it is like to eat very little or nothing at all, and whether good mouth care will make the process tolerable. In roughly one out of six cases the patient reconsiders the decision not to eat and drink. If the patient indicates that he has doubts about his decision, it is important to discuss this with the patient and to examine his initial decision from various angles by discussing the advantages and disadvantages. Those close to the patient should be involved in this discussion, unless the patient explicitly objects to this. In the end it is the patient who decides whether to stand by his decision not to eat and drink or to reconsider it.

5.5.2 General personal care and skin care

Whether, and to what extent, personal care is necessary depends on the patient's physical condition. Care may sometimes be necessary from the outset, and in other cases only during the course of the process. In all cases the patient will ultimately need to receive total personal care. Personal care tasks are performed by the nurse/carer, volunteer (in the hospice) and/or those close to the patient. If the latter do take on all or only a number of personal care tasks, the nurse/carer must ensure they receive the proper instructions.

The patient's comfort takes precedence. The patient's wishes and expectations regarding care and/or nursing are agreed in consultation with the patient. The arrangements concerning the procedure for care and/or nursing (washing, dressing, cleaning the bedclothes, the products to be used (such as impregnated face and body cloths, care products) and turning, if needed) should be recorded in the care plan.

The provision of a high-low bed (to allow others to provide effective care), an anti-decubitus mattress and/or anti-decubitus cushions for the chair was arranged during the preparatory phase. Heel protectors should also be used, where necessary.

Good skin care is vital. In the event decubitus or other skin problems occur, a specialist nurse should be consulted. See the national guidelines on decubitus and blemishes (V&VN Dutch Nurses' Association, 2011-I and II).

Self-evidently a number of the routine nursing procedures performed mainly in hospital (such as taking the patient's temperature or blood pressure) will no longer be carried out.

5.5.3 Mouth care

Thirst or a dry mouth are caused by dehydration of the oral mucosa. Good mouth care is essential to help prevent complaints of dry mouth and feeling thirsty as far as possible. Mouth care should be initiated at a time when the patient is not yet experiencing these complaints. Initially the patient will sometimes be able to carry out mouth care independently, but he will gradually grow more dependent on others. Where possible, those close to the patient should be involved in performing mouth care since they will usually be at the patient's bedside most of the time. They must, however, receive the proper instructions.

The care provider (usually the nurse, and occasionally the physician) should thoroughly examine the patient's mouth at least once a day to enable the early detection of mouth problems. This process requires good lighting (a pocket lamp), gloves and (wetted) tongue depressors or a piece of gauze.

The lips, buccal mucosa, the tongue, the floor of the mouth, the gums and the teeth or dentures should be inspected. A mouth status score may be used for this purpose.

Mouth care consists of the following:

- ▶ Refreshing the mouth using:
 - an atomised water spray (a small plant spray or Eau de Cologne bottle); three puffs contain around 2 cc of water (as often as needed);
 - half an ice cube, crushed and wrapped in a gauze, which the patient can suck; an ice cube contains around 55 cc of water (as often as needed);
 - a sugar-free ice lolly;
 - in the event of bad breath: mint-flavoured mouth spray or a mouth spray containing chlorhexidine, cetylpridinium chloride and zinc lactate (Halita®) (spray on the tongue 2-3x daily with 3-4 puffs).
- ▶ Saliva discharge may also be stimulated by using sugar-free chewing gum or sugar-free sweets (provided the patient can still chew or suck).
- ▶ Mouth-moistening products or saliva substitutes may also be used (especially for sleeping, to prevent the mucous membranes from drying out 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 daily;
 - Saliva Orthana® gel or spray, as needed.
- ▶ Rinsing the mouth with physiological salt (dissolve a level teaspoon of salt in a glass of lukewarm tap water, 4x daily, or more often if necessary); the patient should subsequently spit out the mouth rinse. If the patient can no longer rinse his mouth, it can be rinsed 4x daily (more often if necessary) with physiological salt using a spray and/or the oral mucosa should be wetted with a moisturised piece of gauze or a cotton bud.
- ▶ Keeping the lips moisturised with a vaseline or lip cream (2x daily, or more often if necessary).
- ▶ Polishing the patient's teeth and molars with a soft toothbrush (2x daily).
- ▶ Cleaning the teeth (interdental) using an interdental brush (1x daily).
- ▶ Cleaning dentures, if worn. Initially the patient can wear dentures (partly depending on the patient's wishes) during the day to enhance the patient's appearance and to facilitate speaking. If the patient no longer wishes to wear dentures or if he has mouth problems, the dentures should also be removed during the day.
- ▶ Cleaning the tongue (if necessary 1x daily) with a soft toothbrush or a tongue scraper.

The mouth can become dehydrated when people breathe through their mouth when sleeping. Should this occur, a steaming device can be placed above the bed, close to the patient's mouth, if necessary.

Most of the required products are not reimbursed by the health insurer and are available from a chemist.

If the patient has a Candida infection (usually characterised by hyperemic mucous membranes, which are mostly covered with a white layer or white spots on the oral mucosa and/or on the tongue), treatment with fluconazole suspension or tablets 1dd 100 mg for 7 days should be considered (if the patient is still able to take oral medication), or by administering one measuring spoon of 20 mg/g 4dd miconazol gel with a finger or cotton bud. Nystatin oral suspension is not recommended on account of the taste and the need for frequent administration.

For more information, see the guideline on mouth complaints issued by the Comprehensive Cancer Centre the Netherlands (IKNL, formerly the Association of Integrated Cancer Centres) (Mank 2010, www.pallialine.nl).

5.6 Implementation phase: middle phase

The duration of the middle phase varies. Depending in part on the severity of any illness the patient may be suffering from, this phase (with a minimum fluid intake) will last no longer than one to two weeks. If the patient has not minimised the amount of fluid he drinks (< 50 ml/24 hours), it may take a few more days to weeks before the patient dies. Furthermore the patient's condition the moment he stops eating and drinking will determine the duration of this period.

If the patient stops eating and no longer or hardly drinks at all, in this phase the patient will grow weaker and become bedridden. Those close to the patient and/or care providers are usually constantly present to provide personal care, mouth care, support and guidance, and to prevent the patient from falling when attempting to get out of bed.

While this period can be very valuable and enriching for those close to the patient, it can be very stressful too. Support and guidance are therefore vital for those close to the patient. For care providers this period likewise can be stressful and they too must be given attention.

During this phase dehydration symptoms will become increasingly severe. Complaints and problems can occur, such as urinary and defecation disorders, pain, nausea/vomiting and restlessness, and confusion and delirium. In the event of an incurable (refractory) symptom which leads to unbearable suffering, intermittent or continuous palliative sedation may be initiated.

The above aspects are discussed below. Needless to say other complaints and problems may also occur during this period, particularly if they already existed before. For information on the treatment of these other complaints and problems, please refer to the book containing guidelines on palliative care published by the Comprehensive Cancer Centre the Netherlands (IKNL, formerly the Association of Integrated Cancer Centres) (De Graeff 2010-II, www.pallialine.nl).

5.6.1 Dehydration

During this phase an increasing level of dehydration will occur. This may have both a favourable and unfavourable effect on a number of existing complaints and problems or (if they do not exist) the probability that they will occur (De Nijs 2010, www.pallialine.nl).

The potential favourable effects include:

- ▶ reduced urine production, which will reduce the need to visit the lavatory, reduce urinary incontinence and reduce the need for a urinary catheter;
- ▶ reduced sputum production, which will reduce coughing;
- ▶ reduced vomiting and reduced diarrhoea;
- ▶ reduced peripheral oedema, ascites, pulmonary oedema or cerebral oedema;
- ▶ less pain due to decreased oedema surrounding a tumour.

The potential unfavourable effects include:

- ▶ a higher risk of urinary infections;
- ▶ dry mucous membranes;
- ▶ harder mucous;
- ▶ constipation;
- ▶ the accumulation of medication excreted through the kidneys involving a higher risk of side effects;
- ▶ a higher risk of developing confusion and delirium.

5.6.2 Urinary and defecation disorders

Urine production will usually decrease significantly in the course of time. Until such time as the patient is unable to do so, it would be preferable for the patient to use the lavatory or a lavatory chair. If the patient is or has become bedridden, the following methods may be used:

- ▶ a bedpan or urinal;
- ▶ incontinence products or a mat;
- ▶ a condom catheter or an indwelling catheter.

For more information, see the guideline on urogenital problems issued by the Comprehensive Cancer Centre the Netherlands (IKNL, formerly the Association of Integrated Cancer Centres) (Van Andel 2010, www.pallialine.nl).

A phosphate enema administered once only to encourage defecation may be considered if the patient stops eating and drinking. If this fails to induce defecation, giving a 10 mg bisacodyl supp every other day may be considered. Defecation usually occurs 30-60 minutes after administration. Otherwise a digital rectal examination should be performed. If the patient has faecal impactions, a phosphate enema should be given or the digital removal of defecation (with a finger) may be performed by the nurse or the physician.

For more information, see the guideline on constipation issued by the Comprehensive Cancer Centre the Netherlands (IKNL, formerly the Association of Integrated Cancer Centres) (De Graeff 2010-II, www.pallialine.nl).

5.6.3 Pain

In some cases the patient may still be using pain killers as maintenance treatment at the time he decides not to eat and drink. Pain alleviation should self-evidently be continued, applying the dose corresponding (and adjusted, if necessary) to the level of pain intensity. If the medication is administered orally, the route of administration should be changed either at an earlier or later stage (see table 5.1). The use of a pain score is recommended.

Paracetamol may be administered rectally, usually in a dosage of 4dd 1000 mg supp.

NSAIDs (diclofenac and naproxen) may be administered (same dosage as the oral dosage) as a suppository. However, these substances are not recommended in view of the patient's generally advanced age and the fact that the kidney function is likely to deteriorate due to dehydration in this phase, increasing the risk of side effects (stomach complaints and delirium).

Since morphine is excreted by the kidneys and therefore the risk of accumulation exists coupled with a higher risk of side effects, fentanyl patches are preferred or slow release oxycodone administered rectally (2/3rds of the oral dosage), both combined with a laxans, such as a bisacodyl supp.

The continuous subcutaneous infusion of opioids using a pump is an alternative but will rarely be necessary. For the reasons outlined earlier, the use of morphine is not recommended here. The continuous infusion of oxycodone has preference. See table 5.2 for the conversion factors when using opioids.

When using opioids as maintenance treatment, medication must be available to treat breakthrough pain. Given that it is only administered on an occasional basis, the objection against using morphine here lapses. The following treatment may be given for breakthrough pain:

- ▶ immediate release morphine:
 - orally (a drink) or rectally (both in a dosage of 1/6th of the daily oral dosage; when using fentanyl 1/6th of the corresponding daily oral dosage of morphine should be given, see table 5.2).
 - subcutaneously or intravenously (again 1/6th of the daily subcutaneous dosage).

- ▶ immediate release oxycodone: orally (tablet or a drink) or subcutaneously/intravenously (both again in a dosage of 1/6th of the daily dosage (converted or otherwise).
- ▶ rapid-acting fentanyl (see table 5.1). When administering these substances for the first time, they should be administered in the lowest dosage (so irrespective of the maintenance medication).

Table 5.2 Opioid conversions

Morphine		Fentanyl	Oxycodone		Hydromorphone	Tramadol	Buprenorphine
Oral	SC/IV	Patch	Oral	SC/IV	Oral	Oral	Patch
mg per 24 hours	mg per 24 hours	µg per hour	mg per 24 hours	µg per hour			
30	10	12	15	7.5	4 ¹	150	
60	20	25	30	15	8	300	
120	40	50	60	30	16	- ²	52.5
180	60	75	90	45	24	-	
240	80	100	120	60	32	-	105
360	120	150	180	90	48	-	- ³
480	160	200	240	120	64	-	-

¹ This dosage cannot be given in practice since the lowest dosage of the slow release preparation is 4 mg and the substance must be given twice daily.

² Dosages exceeding 400 mg/daily are not recommended.

³ Dosages exceeding 140 µg hourly are not recommended.

Even if the patient is not in pain initially, pain killers will be prescribed and given to the patient to self-administer according to his needs. Lying in a hospital bed for a prolonged period and sometimes skin complaints can cause pain complaints in the course of the process. Initially, paracetamol suppositories will suffice (1,000 mg supp to 4dd, if necessary). If this has insufficient effect, immediate release morphine is an option (if necessary 5-10 mg orally or rectally, possibly 2.5-5 mg subcutaneously or intravenously), immediate release oxycodone 2.5-5 mg, possibly 2-4 mg subcutaneously or intravenously). If this has insufficient effect, the dosage should be increased.

There may be side effects, such as drowsiness, constipation, nausea, vomiting and delirium, particularly in patients who have never used opioids before.

For more information, see the guideline on pain issued by the Comprehensive Cancer Centre the Netherlands (IKNL, formerly the Association of Integrated Cancer Centres) (De Graeff 2010-IV, www.pallialine.nl).

5.6.4 Nausea and vomiting

Nausea and/or vomiting may occur as a side effect of medication (mainly opioids), in conjunction with constipation or as a symptom of the consequences of an underlying illness (for instance disturbed gastric emptying or ascites due to obstruction of the stomach or bowels).

Initially metoclopramide 3-4dd 10 mg supp or subcutaneously should be given, or domperidon 2dd 60 mg supp, or haloperidol 2dd 0.5-2 mg (5-20 drops) via the cheek pouch or subcutaneously. If this has an insufficient effect, levomepromazine 6.25mg should be given subcutaneously or via the cheek pouch. Dexamethasone (as an antiemetic) is not given in principle because of its appetite stimulant effect.

For more information, see the guideline on nausea and vomiting issued by the Comprehensive Cancer Centre the Netherlands (IKNL, formerly the Association of Integrated Cancer Centres) (De Graeff 2010-V, www.pallialine.nl).

5.6.5 Restlessness, confusion and delirium

Restlessness may occur due to the following:

- ▶ symptoms which are insufficiently under control (such as pain or shortness of breath);
- ▶ a full bladder or full rectum;
- ▶ bladder spasms when using a bladder catheter;
- ▶ anxiety;
- ▶ the side effects of medication (such as metoclopramide, dexamethasone or diazepam);
- ▶ medication withdrawal symptoms (mainly opioids, corticosteroids, benzodiazepines), alcohol, nicotine or drugs;
- ▶ delirium.

Delirium is characterised by the presence of fluctuating disorders of consciousness and attention as well as a change in cognitive functions (disorders involving memory, orientation in time and place, and thinking and perception (delusions and/or hallucinations)). The symptoms occur within a short space of time, fluctuate during the course of the day and often are the most intense at night. Delirium may be accompanied by restlessness (hyperactive delirium) and/or apathy (silent delirium). Delirium is often preceded by signs, such as day-night rhythm disturbance, 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 choose not to eat and drink as a consequence of the following:

- ▶ the patient's often advanced age;
- ▶ dehydration;
- ▶ medication (mainly opioids);
- ▶ approaching death.

Delirium is a very unpleasant experience, not only for the patient but also for those close to the patient and for the care providers. It is important to recognise and treat early-stage delirium. Given that delirium can fluctuate considerably in the course of the day and night, the observations of nurses, carers and those close to the patient are vital. A Delirium Observation Scale can be used for this purpose (DOS, see the guideline on delirium (Bannink 2010, www.pallialine.nl)). The nurse or carer draws up a score three times every 24 hours based on observations. A low score means that delirium is unlikely. A score of 3 or higher is associated with delirium but does not serve as proof of the disorder. The physician makes a diagnosis on the basis of the clinical profile.

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

- ▶ providing orientation points (a clock, photos in the room, familiar faces at the patient's bedside);
- ▶ avoiding too many simultaneous stimuli (noise, images);
- ▶ using glasses and/or a hearing aid;
- ▶ not abruptly discontinuing opioids, benzodiazepines or corticosteroids, particularly if they are given in high dosages and/or have been used for a long time;
- ▶ placing a nicotine patch on patients who were excessive smokers.

The best treatment for delirium is to treat the triggering factors, by for instance changing medication, treating bladder retention or correcting dehydration. The treatment of the triggering factors in a patient who has stopped eating and drinking, however, is usually not at issue. A catheter is inserted in the event of bladder retention. If opioids induce delirium, opioid rotation (substitution of one type of opioid with another) or sometimes reducing the dosage may be an option.

In the context of a patient who has stopped eating and drinking an exceptional situation may arise whereby the delirious patient asks for something to drink. If the patient insistently and repeatedly demands fluid, this could create a difficult situation. On the one hand, it may be extremely difficult to refuse the patient's request, while, on the other, a person close to the patient or the care provider wishes to adhere to the agreements made by the patient at the time he had capacity to decide. When this occurs, the parties concerned can fall back on the agreements made during the preparatory phase and/or in the patient's living will (see Sections 5.4.1 and 5.4.4).

It is imperative for care providers, particularly if a difficult situation arises, not to suddenly interfere with the agreements previously made with patients and offer them something to drink. If patients are offered fluid, they will fail to reach their desired goal. For this reason it is essential to prevent and treat delirium using the non-pharmacological measures described below, in addition to pursuing an anticipatory policy, combined 'where necessary' with medication policy in the event the patient becomes restless or delirious.

Non-pharmacological measures are an important element of treatment and involve the same measures as those explained under prevention. The objective is to create a tranquil, stable and safe environment. The constant presence of a familiar face can play an important role here. It is important to explain the patient's condition to those close to the patient and how to deal with it. It is important to communicate calmly and clearly with the patient and not to contradict delusions or hallucinations. It should also be emphasised that talking to or making agreements with the patient is futile. In the majority of cases the patient must be deemed to lack capacity to decide when showing symptoms of delirium. Measures to protect the patient from climbing out of bed and falling (bed rails, immobilisation) often have the reverse effect. They should only be taken as a last resort and only after they have been explained to, and consent has been granted by those close to the patient.

For pharmacological treatment, please refer to the guideline on delirium issued by the Comprehensive Cancer Centre the Netherlands (IKNL, formerly the Association of Integrated Cancer Centres) (Bannink 2010, www.palliative.nl), and the guideline on delirium in adults issued by the Netherlands Society of Clinical Geriatrics (NVKG). Haloperidol is the substance of choice. However, having regard to dehydration and the patient's short life expectancy, treatment with haloperidol is often soon combined with benzodiazepines or, as the case may be, initiating palliative sedation.

5.6.6 Palliative sedation

Palliative sedation is the deliberate lowering of a patient's level of consciousness in the final stage of life (KNMG 2009). The objective is to relieve otherwise untreatable suffering (rather than shortening life) by lowering the patient's level of consciousness. This suffering arises from one or several untreatable refractory or other symptoms. A symptom is, or becomes, refractory if none of the conventional modes of treatment is effective or sufficiently fast-acting, and/or if these modes of treatment are accompanied by unacceptable side-effects.

The symptoms in a patient who has stopped eating and drinking will often be exhaustion and/or delirium, but sometimes persistent thirst (as well), despite good mouth care. This is referred to as a refractory situation in that the patient has not granted consent to offer or artificially administer fluid (the symptom therefore is untreatable) and the intake of fluid could lead to prolonging the patient's life against their express wishes, which in this context is deemed an unacceptable side effect. If the patient is additionally experiencing unbearable suffering in this situation, this means that there is an indication for palliative sedation. If a patient had already been treated with opioids and/or anti-psychotic drugs, this medication must be continued, but only to control pain, shortness of breath and/or delirium.

Palliative sedation should be applied proportionately, in other words to lower the level of consciousness to the degree that is necessary and sufficient to relieve suffering. The effect is measured in terms of the patient's comfort rather than the degree by which the level of consciousness is lowered. In some cases a slight lowering of the level of consciousness will suffice to relieve suffering (superficial sedation). In that case the patient will retain the ability to communicate. In practice deep sedation is often applied, which will erase the possibility of communicating.

Sedation may be applied intermittently (usually only at night), for a short period of time (once only as time-out) or continuously. The benefit of intermittent sedation is that the patient will still be able to communicate during the day. Particularly if the patient experiences difficult and restless nights (despite sleeping medication) intermittent sedation may be initiated as the first step.

Continuous deep sedation is subject to the condition that the patient's life expectancy is no longer than one to two weeks. If the patient no longer or scarcely drinks fluid, this condition has been fulfilled. If doubts arise about the consistency of the patient's decision not to eat and drink, continuous sedation is not recommended.

The patient's consent for initiating palliative sedation is not required. This applies in particular to the situation of refractory delirium, where the patient is deemed to lack capacity to decide. In this situation consultation with those close to the patient is desired, but not required.

It is important to emphasise that palliative sedation does not hasten the end of life, provided it is applied in accordance with the guideline.

For the treatment schedule and dosages for the relevant medication, see the guideline on palliative sedation issued by the Comprehensive Cancer Centre the Netherlands (IKNL, formerly the Association of Integrated Cancer Centres) (Verhagen 2010, www.pallialine.nl). This guideline is based on the KNMG guideline on palliative sedation and has identical content.

5.6.7 Guidance for those close to the patient

During all phases of the process, the burden on those close to the patient can be considerable, especially if the process is long, care is intensive, the patient is difficult to approach or offer guidance to, and/or those close to the patient have difficulty in coming to terms with the patient's decision. In such cases those close to the patient face a high risk of becoming stressed, both physically and emotionally.

Signs of stress include:

- ▶ stress reactions, such as a headache, sleeplessness, lack of appetite, tension, nervousness, depression; in serious cases the symptoms include a negative cynical attitude, emotional instability, anger, verbal or physical aggression or aversion to the situation;
- ▶ excessive use of sedatives or tranquillisers;
- ▶ smoking more and/or the increased use of alcohol;
- ▶ feeling guilty or feeling that one has failed in one's duty towards the patient;
- ▶ physical complaints, mainly of the postural and locomotor systems.

It is essential to ensure that those close to the patient receive good information and instructions regarding the patient's care throughout the entire process. Those close to the patient must have an opportunity to take a rest or sleep (by, for instance, using the services of care providers or volunteers at night) and during the day, if desired, to take time out from caring for the patient and to leave the home or the institution.

The guiding principle in supporting those close to the patient is that it will help the care provider anticipate any problems arising sooner or later among those close to the patient. To that end the care provider should regularly speak to those close to the patient about aspects such as:

- ▶ their feelings about the patient's decision;
- ▶ the burden and the strength to cope;
- ▶ the presence of the above signs;
- ▶ satisfaction/dissatisfaction with the care offered by the care providers and/or volunteers;
- ▶ the need for support or further support;
- ▶ worries and fears about what lies ahead.

The spiritual counsellor can additionally assume an important role in offering guidance to those close to the patient.

For more information, see the guideline on informal care issued by the Comprehensive Cancer Centre the Netherlands (IKNL, formerly the Association of Integrated Cancer Centres) (Kuyper 2010, www.pallialine.nl).

5.6.8 Care for the carers

Caring for a patient who has consciously chosen not to eat and drink may also be stressful for care providers and volunteers.

Good information, effective communication among the care providers and volunteers, and the optimal coordination of care are essential to ensure the process proceeds smoothly and to minimise the burden of care as far as possible. During the process attention must also be paid to the emotions of all care providers involved, including volunteers. To that end fixed times every second or third day, for instance, can be arranged during which everyone will have an opportunity to meet up and share their experiences and emotions. The spiritual counsellor can assume an important role in this process.

During a conversation after the patient has passed away, the course of events and the emotions and questions this has elicited among the care providers and volunteers involved can be discussed.

5.7 Implementation phase: dying phase

The dying phase is the phase immediately before the patient's death, denoted by the inevitable approach of death. The patient is expected to die within a few days. In essence the dying phase of patients who have consciously stopped eating and drinking proceeds no differently to that of patients who die as a result of a life-threatening illness.

The onset of the dying phase is established primarily on the basis of careful observation and clinical experience. Nurses and carers have more intense and more frequent contact with the patient, which means they often recognise the onset of the dying phase earlier than the physician.

Signs of approaching death are as follows:

- ▶ extreme fatigue and weakness rendering the patient completely bedridden;
- ▶ reduced urine production;
- ▶ a rapid, weak pulse;
- ▶ extremities that feel cold or may even have cyanotic discolouration, the occurrence of livor mortis;
- ▶ a pointed nose (tightening of the skin on the nose and cheekbones);

- ▶ a lower level of consciousness, often diminishing to complete loss of consciousness (a few hours before death);
- ▶ increasing disorientation, sometimes accompanied by hallucinations and terminal restlessness;
- ▶ audible rattling sounds during breathing (terminal respiratory secretions);
- ▶ irregular breathing shortly before dying (Cheyne-Stokes respiration).

It is important to communicate the onset of the dying phase not only to the patient (if still responsive) and those close to the patient but also to the care providers and volunteers involved.

The following matters should be discussed during the conversation with those close to the patient:

- ▶ their reactions and emotions arising from the onset of the dying phase;
- ▶ what complaints and problems can be expected and how to deal with them; they should be made aware that rattling and Cheyne-Stokes respiration often occur before death but this does not cause the patient to experience shortness of breath.
- ▶ sitting with the patient;
- ▶ the desired rituals in line with personal beliefs/religion and culture.
- ▶ the desired/necessary (additional) services from care providers or volunteers;
- ▶ what should be done when the patient has died.

The provision of personal care to the patient and the treatment of symptoms in essence are no different from the care and treatment described for the middle phase. Ensuring good mouth care is even more important than in the preceding period as the patient is no longer able to do this himself and will often lie in bed with his mouth open for most of the time.

The risk of delirium in the dying phase is higher than in the preceding period. It is essential to recognise the early-stages of delirium or its symptoms and to provide treatment. A potential pitfall here is that restlessness will occur in a patient who is being treated with opioids. It is not uncommon for restlessness to be construed as resulting from an insufficient level of pain control or shortness of breath and that additional opioids are given, and/or the dosage of opioids is increased. In many cases this type of unrest represents terminal delirium and administering additional or higher dosages of opioids will only increase restlessness. Furthermore when restlessness occurs, the possibility of urine retention or constipation should always be borne in mind.

For more information, see the guideline on care in the dying phase issued by the Comprehensive Cancer Centre the Netherlands (IKNL, formerly the Association of Integrated Cancer Centres) (Van Zuylen 2010, www.pallialine.nl).

The death of a patient who has consciously stopped eating and drinking is deemed a natural death. The death documents are completed in the usual manner and will state that the deceased 'chose not to eat and drink' as the immediate cause of death. There is no duty to notify the authorities of such cases, nor is a municipal forensic pathologist required to examine the corpse.

All care providers involved will be notified of the patient's death and in principle a subsequent discussion will be held with them to evaluate the proceedings. A similar discussion will be held with those close to the patient, including the family members.

6 / Dealing with defensive behaviour

6.1 Introduction

The committee has chosen to write the guide primarily for situations in which patients with capacity to decide consciously choose not to eat and drink to hasten the end of life. This chapter briefly discusses patients who display defensive behaviour.

The issue of refusing to eat as a symptom of psychological or psychiatric problems, such as eating disorders, falls beyond the scope of this guide. This also applies to patients receiving compulsory treatment within the framework of the Psychiatric Hospitals (Compulsory Admissions) Act (*Wet bijzondere opnemingen psychiatrische ziekenhuizen*. BOPZ).

6.2 Defensive behaviour

Some patients with dementia, intellectual disabilities or a chronic psychiatric disorder need help when eating and drinking. This ranges from buttering bread or cutting meat and/or encouraging the patient, whether or not repeatedly, to eat and drink, to helping with all aspects of eating and drinking. A number of these patients display what is termed as 'defensive behaviour'. In this context defensive behaviour is taken to mean 'every behaviour displayed by a patient that complicates or prevents eating and drinking'. Resistance to eating and drinking occurs in numerous ways (see table 1), including attempting to pull out a PEG feeding tube which has been in place for a long period of time.

Periods of defensive behaviour may alternate with periods in which the patient does resume eating and drinking. In some cases food is rejected whereas fluid is accepted.

The committee would like to highlight that these patients too may have capacity to decide against eating and drinking to hasten the end of life. In that case these patients do fall within the scope of this guide (see the previous chapters).

It should be noted that the discussion on how to act in cases where a patient who lacks capacity to decide and displays defensive behaviour is presumed to have the wish to die quickly, is only relevant if the patient not only scarcely eats anything but more importantly also reduces his fluid intake, because only then will death be hastened significantly.

If these categories of patients persistently display defensive behaviour and refuse to eat as well as drink, the question may arise of whether it is actually the patient's choice to hasten the end of life this way. Or are there other reasons for eating and drinking less and less or nothing at all? This aspect should always be assessed first.

6.3 Causes of defensive behaviour and how to deal with it

The guideline 'Dealing with defensive behaviour when eating and drinking in residents with dementia' offers guidance on how to deal with this problem in patients with dementia (Groenewoud 2009). It is also useful when dealing with people who have intellectual disabilities.

The underlying cause of the patient's behaviour often is not immediately clear. The causes can roughly be grouped into three categories: unable to eat and drink, not wanting to eat and drink and not understanding the hows and whys of eating and drinking (see table 2).

In cases where a patient who lacks capacity no longer eats and drinks regularly despite being offered help, besides the observations of nurses, carers and those close to the patient, it is crucial for the physician to observe the patient's behaviour several times for himself. This will generate important differential diagnostic information, in that it will also become clear to the physician whether the patient does not want to eat or drink, is unable to eat or drink, or no longer seems to understand the hows and whys of needing to eat and drink.

A complete physical examination, supplemented where necessary with a specialist examination, can often bring to light any somatic causes underlying defensive behaviour. An inspection of the mouth, for instance, will help detect a candida infection (oral thrush) or determine whether the patient is wearing ill-fitting dentures or whether his dentures are giving him pressure ulcers. The inspection will also help assess whether the patient has an extremely dry mouth, perhaps caused by dehydration or the anticholinergic effects of medication. Attention must also be given to whether or not the patient has problems swallowing or swallowing apraxia (if assessable). Moreover it is important to verify whether the patient's behaviour is caused by delirium, anxiety (choking, for example) or a psychotic disorder.

Care providers must be wary of drawing rapid conclusions from the patient's defensive behaviour, but should focus on uncovering the possible causes and offering treatment, where necessary. If defensive behaviour is too quickly deemed to be an indication of intent and the parties concerned go along with a presumed wish to die, care may devolve into neglect. Conversely, force feeding and drinking or the artificial administration of food and fluids may devolve into coercion and duress.

The skill is to constantly look at the patient's overall picture and to allow him to make a decision for himself as far as possible, or with the help of someone close to him or a representative and/or a care provider. In practice this means providing compassionate care, devoting attention to the patient and finding alternative ways to offer food and drink. Care providers should keep their eyes and ears open for all verbal and non-verbal signs and reactions from the patient with a view to uncovering the potential causes of defensive behaviour, on the one hand, and a possible wish to die, on the other.

In the care sectors for people with intellectual disabilities, the elderly, as well as patients suffering from a chronic psychiatric disorder, carers often have intense, long-standing ties with their patients. The bond with the patient, especially patients with intellectual disabilities, are sometimes as intense or even more intense than the bond the family has with the patient. Carers often have an aptitude for interpreting patients' non-verbal signs and consequently play an important role in interpreting defensive behaviour. Day-to-day practice has shown that carers often find it difficult to stop offering food and drink. It is vital to ensure that carers receive support and guidance. See also Section 4.8.

6.4 The role of a written living will and/or the patient's representative

The committee has limited this section to describing the situation in which the patient persistently displays defensive behaviour and refuses both food and drink or tube feeding that is already being administered (by, for example, removing the PEG feeding tube). It is up to the care providers involved to determine in conjunction with the appropriate specialists and those close to the patient how to interpret the patient's defensive behaviour in the light of the patient's capacity/lack of capacity to decide to stop eating and drinking.

The role of a written living will (also known as an advance directive or advance care plan) and the representative of a patient who is deemed to lack capacity to decide are explained below.

1 A written living will

The patient may, at the time he still had decision-making capacity, have declared in writing that he has emphatically decided against food and drink being offered as the illness progresses, and against the artificial administration of food and fluids, for the purpose of hastening the end of life. If the patient displays defensive behaviour and the potential causes have been ruled out, food or drink will no longer be offered, nor will the artificial administration of food and fluids be initiated (see Section 2.6).

With the exception of patients suffering from non-congenital brain damage, this situation will rarely occur in a patient with a severe intellectual disability, since the disability often already existed at birth and consequently there never was an opportunity to draw up a living will.

2 There is no living will, but there is a representative

If the patient displays defensive behaviour and the potential causes have been ruled out, it is important to obtain the view of the patient's representative so that the patient's will can be reconstructed in relation to the latter's current interests. In this situation it would be useful to consider the patient's biography and to talk to those close to the patient to find out what their views are.

3 There is no living will, nor is there a representative

If the patient displays defensive behaviour and there neither is a living will nor a patient representative, the care providers will need to weigh the matter themselves.

Table 1: Examples of defensive behaviour

Before a meal

The resident:

- ▶ refuses to go to the eating area.

During the meal

The resident does not take a bite or a sip:

- ▶ verbally refuses (I won't);
- ▶ does not touch the food;
- ▶ pushes his spoon or plate, or the carer/carer's hand, away;
- ▶ bites on the spoon;
- ▶ turns his head away;
- ▶ keeps his mouth closed;
- ▶ clamps his teeth;
- ▶ walks away from the table.

The resident takes a bite and a sip but does not swallow:

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

Groenewoud JH, Lange J de. Guideline on 'Dealing with defensive behaviour when eating and drinking in residents with dementia'. Kenniskring Transitie in Zorg, Hogeschool Rotterdam, 2009.

Table 2: Possible causes of defensive behaviour**Unable to eat and drink**

- ▶ (eating) apraxia, a chewing or swallowing disorder (arising from dementia);
- ▶ problems chewing or swallowing (dry mouth, denture problems or an inflamed and sore mouth);
- ▶ Physical complaints (fatigue, pain);
- ▶ difficulty eating and swallowing because of the wrong sitting posture, for example sitting hunched forward in a chair;
- ▶ the consistency of the food and drink is not suitable (too liquid or too firm);
- ▶ the patient has a psychiatric disorder: anxiety, feels unsafe, suspicious, stress, easily distracted, concentration problems.

Does not want to eat and drink

- ▶ the patient has a decreased appetite due, for example, to depression, the side effects of medicines, infection, cancer, error of metabolism;
- ▶ the patient does not want any help with eating and drinking;
- ▶ dissatisfied with the food: it does not look appetising, is too cold, and does not taste good;
- ▶ the patient's wish to die.

Failure to understand the hows and whys of eating and drinking

- ▶ diminished sense of taste and/or smell;
- ▶ the patients does not recognise the food;
- ▶ the patient does not recognise feeling hungry and thirsty;
- ▶ the patient regards the carer as a stranger;
- ▶ the patient does not understand the carer's instructions.

Source: Groenewoud JH, Lange J de. Guideline on 'Dealing with defensive behaviour when eating and drinking in residents with dementia'. Kenniskring Transitie in Zorg, Hogeschool Rotterdam, 2009.

I / Appendix I KNMG's position on euthanasia and professional responsibility

Patients have the right to request euthanasia, but physicians are not obliged to grant their request: fundamental objections to euthanasia and assisted suicide must be respected. Euthanasia and assisted suicide are deemed extraordinary medical procedures.

However, professional standards do dictate that physicians give their patients clear and timely information about their personal views. For this reason it is important that physicians first and foremost determine for themselves if they, in principle, are willing to perform euthanasia or assisted suicide. The KNMG holds the opinion that if a physician is not prepared to consider a request for euthanasia from his patient, then he also should not initiate the procedure. In that case, it is his duty to put his patient in touch with a colleague who does not have fundamental objections to euthanasia and assisted suicide. Though there is no legal obligation for physicians to refer patients, they have a moral and professional duty to provide patients with timely assistance in finding a physician (for example within the practice) who does not have fundamental objections to euthanasia and assisted suicide (KNMG 2011-1).

If the physician questions whether he can and wants to comply with the request, he may consult a doctor at SCEN, an organisation offering support and consultation in euthanasia in the Netherlands. Their role includes offering support to physicians. On the basis of a programmatic and substantiated analysis, SCEN doctors provide clear insight into the unbearable and lasting nature of suffering to enable the physician to form his own professional opinion. If the SCEN doctor has held a formal consultation and concludes that the due criteria have not been fulfilled, the physician may consider consulting another SCEN doctor (KNMG 2011-I and 2011-II).

In some cases a physician may also feel or become unable to carry out a request to end life or an assisted suicide on account of personal views, even though he has no fundamental objections to euthanasia and assisted suicide and all the due care criteria set out in the Euthanasia Act seem to have been fulfilled. In such situations, the physician must explain to the patient why he cannot grant the request and, preferably, transfer the patient to a colleague in good time.

Vague promises, failure to transfer patients during absences, causing delays or indicating at a late stage or too late that the physician has reconsidered his decision to perform euthanasia all demonstrate a lack of professionalism. The KNMG therefore calls on all physicians to act as they would wish themselves or their loved ones to be treated.

II / Appendix II Committee composition

- ▶ **Dr. A. (Alexander) de Graeff**, *internist-oncologist and hospice physician*, University Medical Center Utrecht and hospice Demeter, De Bilt, **chair**
- ▶ **Dr J.J.M. (Hans) van Delden**, *elderly care specialist*, professor of Medical Ethics, department of Medical Humanities, Julius Center for Health Sciences and Primary Care, University Medical Center Utrecht, **vice-chair**
- ▶ **R.H.P.D. van Deijck (Rogier)**, *elderly care specialist and palliative care consultant*, De Zorggroep, Dutch Association of Elderly Care Physicians and Social Geriatricians (Verenso), Utrecht
- ▶ **A.M.S. (Aty) van Aarnhem**, *general practitioner*, Dutch College of General Practitioners (NHG), Utrecht
- ▶ **R.S. (Ruben) van Coevorden**, *general practitioner*, palliative care consultant and hospice physician, Immanuel Jewish Hospice, Amsterdam
- ▶ **Dr. B.E. (Boudewijn) Chabot**, *psychiatrist (non-practising) and researcher*, research area: humane voluntary termination of life, Haarlem
- ▶ **P.J.W.B. (Patricia) van Mierlo**, *clinical geriatrician*, medical palliative care consultant, Rijnstate Ziekenhuis Arnhem, Netherlands Society of Clinical Geriatrics (NVKG).
- ▶ **J.F.A.M. (Jeroen) Janssens**, *elderly care specialist*, lecturer, department of Public Health and Primary Care, Leiden University Medical Center, Medical Advisory Committee of the Dutch Association for Voluntary Euthanasia (NVVE)
- ▶ **A. (Anita) Krans**, *nurse specialist in chronic diseases*, V&VN Dutch Nurses' Association palliative nursing, Utrecht
- ▶ **A.D. (Sandra) van Dalen**, *communication specialist*, district nurse Amersfoort, member of the V&VN Dutch Nurses' Association district nursing group, Utrecht
- ▶ **L. (Bert) Prinsen**, *minister*, formerly nursing home pastor, Protestant-Christian Senior Citizens' Association (PCOB), Zwolle
- ▶ **T. (Tielke) Ausems-van Herten**, *physician*, Union of Catholic Senior Citizens' Associations (KBO), 's-Hertogenbosch
- ▶ **E.H.J. (Eric) van Wijlick**, *KNMG policy adviser*, Utrecht, **secretary**

Conflict of interests

- ▶ **Dr. B.E. (Boudewijn) Chabot**, *psychiatrist (non-practising)*, Haarlem; author of the book *Uitweg* (Way Out). (Chabot BE, Braam S. *Uitweg*. Amsterdam: Nijgh & Van Dietmar, 2012).

III / Appendix III Experts consulted

- ▶ **Dr G.A. den Hartogh**, *emeritus professor of Ethics*, University of Amsterdam
- ▶ **Prof. R.T.C.M. Koopmans**, *professor of Elderly Care Medicine*, Radboud University Nijmegen Medical Center
- ▶ **Prof. A.L. Francke**, *professor of Nursing and Care*, VU University Medical Center Amsterdam/NIVEL
- ▶ **Prof. C.M.P.M. Hertogh**, *professor of Elderly Care Medicine & Geriatric Ethics*, VU University Medical Center Amsterdam
- ▶ **Prof. C. Leget**, *professor of Ethics of Care and Spiritual Guidance and professor by special appointment of Palliative Care*, University of Humanistic Studies
- ▶ **Prof. K.C.P. Vissers**, *professor of Palliative Care*, Radboud University Nijmegen Medical Center
- ▶ **Prof. S.E.J.A de Rooij**, *professor of Internal Medicine and Geriatric Medicine*, Academic Medical Centre, Amsterdam
- ▶ **Dr. M. Tonino**, *physician for persons with intellectual disabilities*, Dutch Society of Physicians for Persons with Intellectual Disabilities (NVAVG)

IV / Appendix IV References

- ▶ Aarnhem A van. *Stoppen met eten en drinken*. Pallium 2011, no. 2: 8-10. Van Aarnhem 2011-I.
- ▶ Aarnhem A van, Chabot B.E. Stoppen met eten en drinken. Pallium 2011, no. 4: 8-10. Van Aarnhem 2011-II.
- ▶ Andel G van, Buijl H, Doorn HC van, Pastoor H. *Richtlijn urogenitale problemen, fistels, loze aandrang en tenesmi*. In: Graeff A de, Bommel JMP van, Deijck RHPD van, Eynden BRLC van den, Krol RJA, Oldenmenger WH, Vollaard EH (red). *Palliatieve zorg: richtlijnen voor de praktijk*. Heerenveen, Jongbloed bv, 2010, pp. 697-722. Available via www.pallialine.nl.
- ▶ AVVV/NU'91/KNMG. *Handreiking voor Samenwerking Artsen, Verpleegkundigen en Verzorgenden bij Euthanasie*. Utrecht, 2006.
- ▶ Bannink M, Graeff A de, Monster H. *Richtlijn delier*. In: Graeff A de, Bommel JMP van, Deijck RHPD van, Eynden BRLC van den, Krol RJA, Oldenmenger WH, Vollaard EH (red). *Palliatieve zorg: richtlijnen voor de praktijk*. Heerenveen, Jongbloed bv, 2010, pp. 183-202. Available via www.pallialine.nl.
- ▶ Bernat, BL, Gert B, Mogielnicki RP. *Patient refusal of hydration and nutrition*. An alternative to physician-assisted suicide or active euthanasia. Arch Intern Med 1993, 153: 2723-28.
- ▶ Berry ZS. *Responding to suffering: providing options and respecting choice*. J Pain Symptom Manage 2009, 38: 797-800.
- ▶ Brendel R. *On "Distinguishing among irrational suicide, rational suicide, and other forms of hastened death: implications for clinical practice" by Cavin P. Leeman, M.D.* Psychosomatics 2009, 50: 193-4.
- ▶ CBS: www.cbs.nl/statline.
- ▶ Cantor NL. *The straight route to withholding hand-feeding and hydration*. Am J Bioeth 2009, 9: 57-8.
- ▶ Chabot BE. *Sterven op drift*. Nijmegen, Sun, 1996. Chapter 8: Sterven een oude weg naar Rome.
- ▶ Chabot BE. *Sterfwerk*. De dramaturgie van zelfdoding in eigen kring. Nijmegen: SUN, 2001.
- ▶ Chabot BE. *Auto-euthanasie*. Verborgene stervenswegen in gesprek met naasten. Amsterdam, Uitgeverij Bert Bakker, 2007.
- ▶ Chabot BE, Goedhart A. *A survey of self-directed dying attended by proxies in the Dutch population*. Social Science & Medicine 2009, 68: 1745-51.
- ▶ Chabot BE, Braam S. *Uitweg*. Amsterdam: Nijgh & Van Dietmar, 2013.
- ▶ Eddy D. *A conversation with my mother*. JAMA 1994, 272: 179-81.
- ▶ Cochrane TI. *Unnecessary time pressure in refusal of life-sustaining therapies: fear of missing the opportunity to die*. Am J Bioeth 2009, 9: 47-54.
- ▶ Ganzini, Goy ER, Miller LL, Harvath TA, Jackson A, Delorit MA. *Nurses' experiences with hospice patients who refuse food and fluids to hasten death*. N Engl J Med 2003, 349: 359-65.
- ▶ Gert B, Bernat JL, Mogielnicki RP. *Physician involvement in voluntary stopping of eating and drinking*. Ann Intern Med 2002, 137: 1010-1.
- ▶ Graeff A de, Leermakers J, Hesselman GM. *Richtlijn anorexie en gewichtsverlies*. In: Graeff A de, Bommel JMP van, Deijck RHPD van, Eynden BRLC van den, Krol RJA, Oldenmenger WH, Vollaard EH (red). *Palliatieve zorg: richtlijnen voor de praktijk*. Heerenveen, Jongbloed bv, 2010, pp. 527-574. Available via www.pallialine.nl. De Graeff 2010-I.
- ▶ Graeff A de, Bommel JMP van, Deijck RHPD van, Eynden BRLC van den, Krol RJA, Oldenmenger WH, Vollaard EH (red). *Palliatieve zorg: richtlijnen voor de praktijk*. Heerenveen, Jongbloed bv, 2010. Available via www.pallialine.nl. De Graeff 2010-II.
- ▶ Graeff A de, Krol RJA. *Richtlijn obstipatie*. In: Graeff A de, Bommel JMP van, Deijck RHPD van, Eynden BRLC van den, Krol RJA, Oldenmenger WH, Vollaard EH (red). *Palliatieve zorg: richtlijnen voor de praktijk*. Heerenveen, Jongbloed bv, 2010, pp. 497-510. Available via www.pallialine.nl. De Graeff 2010-III.
- ▶ Graeff A de, Verhagen EH, Besse TC, Crul BJP, Krol RJA. *Richtlijn pijn*. In: Graeff A de, Bommel JMP van, Deijck RHPD van, Eynden BRLC van den, Krol RJA, Oldenmenger WH, Vollaard EH (red). *Palliatieve zorg: richtlijnen voor de praktijk*. Heerenveen, Jongbloed bv, 2010, pp. 527-574. Available via www.pallialine.nl. De Graeff 2010-IV.

- ▶ Graeff A de, Molenkamp CM, Hesselmann GM. *Richtlijn misselijkheid en braken*. In: Graeff A de, Bommel JMP van, Deijck RHPD van, Eynden BRLC van den, Krol RJA, Oldenmenger WH, Vollaard EH (red). *Palliatieve zorg: richtlijnen voor de praktijk*. Heerenveen, Jongbloed bv, 2010, pp. 447-468. Available via www.pallialine.nl. De Graeff 2010-V.
- ▶ Groenewoud JH, Lange J de. *Richtlijn 'Omgaan met afweergedrag bij eten en drinken bij bewoners met dementie'*. Kenniskring Transitie in Zorg, Hogeschool Rotterdam, 2009.
- ▶ Harvath TA, Miller LL, Goy E, Jackson A, Delorit M, Ganzini L. *Voluntary refusal of food and fluids: attitudes of Oregon hospice nurses and social workers*. *Int J Palliat Nurs* 2004, 10: 236-41; discussion 242-3.
- ▶ Heide A van der, Muller MT, Kester JGC, Groenewoud JH, Wal G van der, Maas PJ van der. *Frequentie van het afzien van (kunstmatige) toediening van voeding en vocht aan het levenseinde*. *Ned Tijdschr Geneesk* 1997, 141: 1918-24.
- ▶ Heide A van der, Brinkman-Stoppelenburg A, Delden JJM van, Onwuteaka-Philipsen BD. *Sterfgevallenonderzoek 2010*. Euthanasie en andere medische beslissingen rond het levenseinde. The Hague: ZonMw, 2012. Van der Heide 2012-I.
- ▶ Heide A van der, Legemaate J, Onwuteaka-Philipsen BD, Bolt E, Bolt I, Delden JJM van, Geijtema E, Snijdewind M, Tol D van, Willems DL. *Tweede evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*. The Hague: ZonMw, 2012. Van der Heide 2012-II.
- ▶ Hertogh CMPM, Deerenberg-Kessler W. *Scripta manent? Over tekstverklaring en de wil op schrift*. *Ned Tijdschr Geneesk* 1995, 26: 1313-16.
- ▶ Ivanovic N, Büche D, Fringer A. *Voluntary stopping of eating and drinking at the end of life - a 'systematic search and review' giving insight into an option of hastening death in capacitated adults at the end of life*. *BMC Palliat Care* 2014; 13:1.
- ▶ Jacobs S. *Death by voluntary dehydration - What the caregivers say*. *N Engl J Med* 2003, 349: 325-6.
- ▶ Jansen LA. *No safe harbor: the principle of complicity and the practice of voluntary stopping of eating and drinking*. *J Med Philos* 2004, 29: 61-74.
- ▶ Kerndt P, Naughton JL, Driscoll CE et al. *Fasting: The History, Pathophysiology and Complications*. *The Western Journal of Medicine* 1982, 137: 379-99.
- ▶ KNMG. *Commissie Aanvaardbaarheid Levensbeëindigend Handelen*. Medisch handelen rond het levenseinde bij wilsonbekwame patiënten. Houten/Diegem: Bohn, Stafleu Van Loghum, 1997.
- ▶ KNMG. *Van Wet naar praktijk*. Implementatie van de WGBO. Deel 2: Informatie en toestemming. KNMG, 2004. Available via: www.knmg.nl bij patiëntenrechten.
- ▶ KNMG-commissie landelijke richtlijn palliatieve sedatie. *KNMG-richtlijn palliatieve sedatie*. Utrecht: The Royal Dutch Medical Association, 2009.
- ▶ KNMG. *The role of the physician in the voluntary termination of life*. Utrecht: The Royal Dutch Medical Association, 2011. KNMG 2011-I
- ▶ KNMG. *Goede steun en consultatie bij euthanasie*. Richtlijn voor SCEN-artsen. Utrecht: The Royal Dutch Medical Association, 2011. KNMG 2011-II.
- ▶ KNMG. *Tijdig spreken over het levenseinde*. Handreiking om met de patiënt het gesprek aan te gaan. Utrecht: The Royal Dutch Medical Association 2012. KNMG 2012-I.
- ▶ KNMG. *Spreek op tijd over uw levenseinde*. Handreiking om met de dokter te praten. The Royal Dutch Medical Association, 2012. KNMG 2012-II.
- ▶ Koopmans RTCM, Sindram JPC, Dekkers WJM. *Bewust weigeren van vocht en voedsel in een verpleeghuis om te overlijden: een zaak voor dokter en patiënt?* *Ned Tijdschr Geneesk* 2004, 148: 536-9.
- ▶ Koopmans RTCM, en Dekkers JM. *Versterven bij een psychiatrische patiënt: hindernissen voor patiënt, familie en behandelteam*. *Tijdschr Gerontol Geriatr* 2012, 43: 98-102.
- ▶ Kuiper MB, Hesselmann GM, Prins JB. *Richtlijn mantelzorg*. In: Graeff A de, Bommel JMP van, Deijck RHPD van, Eynden BRLC van den, Krol RJA, Oldenmenger WH, Vollaard EH (red). *Palliatieve zorg: richtlijnen voor de praktijk*. Heerenveen, Jongbloed bv, 2010, pp. 431-445. Available via www.pallialine.nl.

- ▶ Leeman CP. *Distinguishing among irrational suicide and other forms of hastened death: implications for clinical practice*. Psychosomatics 2009, 50: 185-91.
- ▶ Leget C, Staps T, Geer J van de, Mur-Arnoldi C, Wulp M, Jochemsen H. *Richtlijn spirituele zorg*. In: Graeff A de, Bommel JMP van, Deijck RHPD van, Eynden BRLC van den, Krol RJA, Oldenmenger WH, Volvaard EH (red). *Palliatieve zorg: richtlijnen voor de praktijk*. Heerenveen, Jongbloed bv, 2010, pp. 637-662. Available via www.pallialine.nl.
- ▶ Lingen C. *Case of Voluntary Starvation: Death on the Tenth Day*. Br Med J 1870, 485: 384-5.
- ▶ Loewy EH. *Terminal sedation, self-starvation, and orchestrating the end of life*. Arch Intern Med 2001, 161: 329-32.
- ▶ Mank AP, Raber-Durlacher JE, Zinger A de, Smit M, Bommel JMP van, Lugt-Lustig K de. *Richtlijn klachten van de mond*. In: Graeff A de, Bommel JMP van, Deijck RHPD van, Eynden BRLC van den, Krol RJA, Oldenmenger WH, Volvaard EH (red). *Palliatieve zorg: richtlijnen voor de praktijk*. Heerenveen, Jongbloed bv, 2010, pp. 469-496. Available via www.pallialine.nl.
- ▶ McCann RM, Hall WJ, Groth-Junker A. *Comfort care for terminally ill patients*. The appropriate use of nutrition and hydration. JAMA 1994, 272: 1263-6.
- ▶ Miller FG, Meier DE. *Voluntary death: a comparison of terminal dehydration and physician-assisted suicide*. Ann Intern Med 1998, 128: 559-62.
- ▶ Nederlandse Vereniging voor Klinische Geriatrie. *Richtlijn delier volwassenen*. Utrecht, 2013.
- ▶ Nijs E de, Graeff A de. *Richtlijn dehydratie en vochttoediening*. In: Graeff A de, Bommel JMP van, Deijck RHPD van, Eynden BRLC van den, Krol RJA, Oldenmenger WH, Volvaard EH (red). *Palliatieve zorg: richtlijnen voor de praktijk*. Heerenveen, Jongbloed bv, 2010, pp. 165-182. Available via www.pallialine.nl.
- ▶ NVVE. *Stoppen met eten en drinken*. Amsterdam: Nederlandse Vereniging voor een Vrijwillig Levensseinde, 2009-5.
- ▶ Owen OE, Caprio S, Reichard GA et al. *Ketosis of Starvation: A Revisit and New Perspectives*. Clinics in Endocrinology and Metabolism 1983, 12: 359-379.
- ▶ Pasma R. *Forgoing artificial nutrition and hydration in nursing home patients with dementia*. Decision making, clinical course and quality of dying. Dissertation VU University Amsterdam, Amsterdam, 2004.
- ▶ Phillips PA, Rolls BJ, Ledingham JGG et al. *Reduced thirst after water deprivation in healthy elderly men*. New England Journal of Medicine 1984, 311: 753-9.
- ▶ Printz LA. *Terminal dehydration, a compassionate treatment*. Arch Intern Med 1992, 152: 697-700.
- ▶ Quill TE, Lo B, Brock DW. *Palliative options of the last resort: a comparison of voluntary stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia*. JAMA 1997; 278: 2099-2104.
- ▶ Quill TE. *Responding to intractable terminal suffering: the role of terminal sedation and voluntary refusal of food and fluids*. Ann Intern Med 2000, 132: 409-14. Quill 2000-I.
- ▶ Quill TE, Lee BC, Nunn S. *Palliative treatments of last resort: choosing the least harmful alternative*. University of Pennsylvania Center for Bioethics Assisted Suicide Consensus Panel. Ann Intern Med 2000, 132: 488-93. Quill 2000-II.
- ▶ Quill TE. *Physicians should "assist in suicide" when it is appropriate*. J Law Med Ethics 2012, 40: 57-65.
- ▶ Rady MY, Verheijde JL. *Distress from voluntary refusal of food and fluids to hasten death: what is the role of continuous deep sedation?* J Med Ethics 2011, doi:10.1136/medethics-2011-100278.
- ▶ Rich KL, Butts JB. *Rational suicide: uncertain moral ground*. J Adv Nurs 2004, 46: 270-8; discussion 278-3.
- ▶ Riet P van der, Brooks D, Ashby M. *Nutrition and hydration at the end of life: pilot study of a palliative care experience*. J Health Law Med 2006, 14: 182-98.
- ▶ Schwarz J. *Exploring the option of voluntarily stopping eating and drinking within the context of a suffering patient's request for a hastened death*. J Palliat Med 2007, 10: 1288-97.
- ▶ Terman SA. *The best way to say goodbye*. A Legal Peaceful Choice at the End of Life. Carsbad, Life Transitions Publications, 2006.

- ▶ Verhagen EH, De Graeff A, Verhagen CAHHVM, Hesselmann GM, Krol RJA. *Richtlijn palliatieve sedatie*. In: Graeff A de, Bommel JMP van, Deijck RHPD van, Eynden BRLC van den, Krol RJA, Oldenmenger WH, Vollaard EH (red). *Palliatieve zorg: richtlijnen voor de praktijk*. Heerenveen, Jongbloed bv, 2010, pp. 589-622. Available via www.pallialine.nl.
- ▶ Vullo-Navich K, Smith S, Andrews M et al. *Comfort and incidence of abnormal serum sodium, bun, creatinine and osmolality in dehydration of terminal illness*. *Am J Hospice and Palliative Care* 1998,15: 770-84.
- ▶ VU University Medical Center, EMGO. *Zorg rond het levenseinde voor mensen met de ziekte van Alzheimer of een andere vorm van dementia*. Een handreiking voor familie en naasten. Amsterdam, second, revised, Dutch edition, 2011. Available via <http://www.vumc.nl/afdelingen/Amsterdam-Center-on-Aging/informatieenmaterialen/Tebestellenmaterialen/Zorg-rond-het-levenseinde/>
- ▶ V&VN Dutch Nurses' Association. *Hoe ga je om met eten en drinken*. Handreikingen voor zorgsituaties waarin eten en drinken en kunstmatige voeding een rol spelen. Utrecht, 2006.
- ▶ V&VN Dutch Nurses' Association. *Omggaan met gewetensbezwaren*. Commissie Ethiek, 2008.
- ▶ V&VN Dutch Nurses' Association. *Landelijke multidisciplinaire richtlijn decubitus*. Preventie en behandeling. Utrecht, 2011. V&VN 2011-I.
- ▶ V&VN Dutch Nurses' Association. *Landelijke multidisciplinaire richtlijn smetten*. Preventie en behandeling. Utrecht, 2011. V&VN 2011-II.
- ▶ World Health Organization. *WHO Definition of Palliative Care, 2002*.
- ▶ Zuylen L van, Veluw H van, Esch J van. *Richtlijn zorg in de stervensfase*. In: Graeff A de, Bommel JMP van, Deijck RHPD van, Eynden BRLC van den, Krol RJA, Oldenmenger WH, Vollaard EH (red). *Palliatieve zorg: richtlijnen voor de praktijk*. Heerenveen, Jongbloed bv, 2010, pp. 663-680. Available via www.pallialine.nl.